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United States Senate

COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS

WASHINGTON, DC 20510-6300

March 6, 2000

Ms. Sandy Thurman
Director
White House Office of National AIDS Policy
736 Jackson Place, N.W.
Washington, D.C. 20503

Dear Ms. Thurman :

Thank you very much for your testimony before the Committee on Health, Education, Labor, and Pensions at its hearing on March 2nd, "The Ryan White CARE Act: Meeting the Challenges of an Evolving HIV/AIDS Epidemic."

As you know, the CARE Act has for ten years provided the basis for medical and support services programs needed in the fight against this terrible disease, which has affected so many sufferers and their loved ones. Thankfully, new forms of treatment and improved systems of care have succeeded in lowering the rate of death and the occurrence of AIDS. However, greater incidence of HIV among rural Americans, women, young people, and members of minority populations makes it essential that we maintain the network of services needed by those still suffering. Our successes, brought by better outreach, testing, and counseling for the most vulnerable in our society, also mean that localities and States need resources to continue giving care.

It is my hope that the Committee will soon complete the work it has begun to formulate bipartisan legislation to reauthorize the Ryan White CARE Act. Your remarks will prove most helpful in our effort to improve this important act.

Thank you again for taking time to be part of the legislative process.

Sincerely,

James M. Jeffords

SPD:mdc

Joseph Kelly <joseph.kelly2@worldnet.att.net>
03/01/2000 05:16:36 PM

Please respond to Joe Kelly NASTAD <jkelly@nastad.org>

Record Type: Record

To: Sandra Thurman/OPD/EOP

cc:
Subject: Testimony

March 2, 2000
>
> Testimony of Rep. Tom A. Coburn, M.D.
> Before the Health, Education, Labor, & Pensions Committee
> United States Senate Hearing on
> Ryan White CARE Act Reauthorization
>
>
> Mr. Chairman, and Members of the Committee, I would like to thank
> you for the opportunity to testify before you today on the reauthorization
> of the Ryan White CARE Act.
>
> As you know, I am a practicing physician who has cared for men,
> women and children from all walks of life affected by HIV/AIDS. And
> despite many of the amazing medical advances that have been made over the
> past decade, it still is a heart wrenching experience for me to have to
> tell any patient of mine that they are infected with this horrible virus
> that will eventually kill them.
>
> I had the opportunity to serve with many of you on the Ryan White
> CARE Act conference committee during the 104th Congress. Much of the
> successes we have seen in recent years such as declining AIDS deaths and
> improvements in the lives of those living with HIV can be attributed to
> this Act, and in particular, the AIDS Drug Assistance Program (ADAP).
> However, new challenges confront us. Women, communities of color,
> adolescents and even older Americans are increasingly becoming impacted by
> HIV. But yet even as the face of AIDS changes, many of the issues we
> faced five and ten years ago are still before us today.
>
> Over 665,000 Americans have been diagnosed with AIDS in the short
> time since this disease was recognized nearly 20 years ago. Over 400,000
> of which have died. The Centers for Disease Control and Prevention
> estimates that today up to 900,000 Americans are living with HIV- many of
> which do not even know they are infected. And despite billions of dollars
> spent on prevention programs, every year 40,000 new HIV infections occur
> in the United States. This number has remained unchanged over the past
> decade. We must ask ourselves, "why are we failing to halt- or even slow
> down- this epidemic?"

>
> Current prevention messages ignore successful interventions that
> have historically curtailed other contagious diseases. Partner
> notification is an extremely effective tool for disease control,
> especially for women. This is because many HIV-infected women- 50 to 70
> percent in some studies- do not engage in high risk behaviors but were
> infected by a partner who does. Without guaranteeing these unsuspecting
> victims a right to know that they are at risk, how else can they protect
> themselves?
>
> Ten years ago, during the original Senate consideration of the Ryan
> White CARE Act, Senator Kennedy stated that "there is a duty to warn."
> But yet a decade later, there still is no right to know if you have been
> exposed to HIV. In fact, the Texas Supreme Court ruled in 1998 that there
> is "no statutory or common-law duty to notify" a woman "that she was at
> risk of contracting the HIV virus."
>
> Stephanie Williams, a black mother from South Carolina, who believed
> she was in a mutually monogamous relationship was infected by her
> boyfriend who has since died of AIDS. Pam McCree, another
> African-American women, became infected in the same way. She only became
> aware of her status after the man who infected her died.
>
> A woman who works at an inner city clinic in New York was forced to
> remain silent while one of her HIV-positive clients attempted to have a
> baby with his wife who was unaware of his status. Another New Yorker only
> learned that she was infected by her husband after their child was
> diagnosed with AIDS during an autopsy. A Hispanic woman from the Bronx
> discovered her status when her husband lay dying of a disease with no name
> and a counselor at the hospital suggested that she be tested for HIV.
>
> These are not isolated incidents. All of these women were allowed
> to become infected by people they trusted. They did not know they were at
> risk and no one warned them. In some cases, the law forbade them from
> being notified. Partner notification is a simple matter of life and
> death. And all too often, silence does indeed equal death.
>
> As more women become infected with HIV, more children have become
> affected by AIDS as well. Science, however, has provided a great
> opportunity to prevent most children from becoming infected themselves.
>
> One of the most promising victories in the battle against AIDS was
> the 1994 finding that administration of the drug ZDV during pregnancy and
> childbirth could significantly reduce the chance that a child of an
> HIV-positive mother would be infected. Using Caesarean section during
> birth, coupled with ZVD, has been found to nearly eliminate
> mother-to-child HIV transmission. Even if treatment begins shortly after
> birth, transmission can still be considerably reduced according to a more
> recent study.
>
> Despite these medical miracles, a significant number of women still
> are not tested for HIV during their pregnancy. As a result, countless
> children are needlessly infected every year with this incurable,
> devastating disease that will prematurely and unnecessarily claim their

> lives.
>
> Five years ago, the House overwhelmingly passed a Ryan White
> reauthorization bill which would have required all pregnant women to be
> counseled and offered an HIV test. In the case that a woman did not
> receive prenatal care or her HIV status was otherwise unknown, the newborn
> would be tested. This approach ensured that no woman or child was left to
> slip through the cracks. The importance of such a policy was underscored
> just this week by a study printed in the Journal of the American Medical
> Association which found that infants are put at a significant risk of
> becoming infected from their mothers by breast-feeding.
>
> As you know, the conference committee rejected the House position
> and instead asked the Institute of Medicine (IOM) to examine the issue and
> make a recommendation.
>
> A year and a half ago- with little fanfare- the IOM issued its
> recommendation which urged "the adoption of a national policy of universal
> HIV testing, with patient notification, as a routine component of prenatal
> care. This position has been endorsed by the American Medical
> Association, the American College of Obstetricians and Gynecologists and
> the American Academy of Pediatrics. Congress should follow suit and enact
> this recommendation which it requested.
>
> No one will ever know how many babies died because we failed to
> address this issue during the last reauthorization. We must not condemn
> any more babies to early deaths.
>
> In addition to women and children, communities of color are
> increasingly affected by HIV/AIDS. To better address the ever changing
> demographics of the epidemic we must shift our focus from AIDS, the end
> stage of the disease, to HIV. The current Ryan White CARE Act formulas
> award grants to cities and states based upon AIDS data. Because AIDS is
> the last stage of HIV disease and develops on average ten or more years
> after infection, this formula is blind to the current extent of the
> epidemic. This means that women, African-Americans and other demographic
> groups which have experienced significant increases in new HIV infections
> that have not yet progressed to AIDS have been neglected, shortchanged and
> often left to fend for themselves.
>
> By refocusing funding formulas from AIDS to HIV cases, these groups
> will not only be ensured more adequate federal support, but they will also
> be guaranteed a greater role in determining how these funds are spent at
> the local level since planning councils are required by law to reflect the
> demographic make-up of the epidemic in an area. As long as these formulas
> are based upon AIDS data, federal resources will be directed to where the
> epidemic was a decade ago rather than where it is today and where it is
> headed.
>
> There are many other issues which we should address during the
> reauthorization process. We must ensure that all states are provided
> adequate funding for their AIDS Drug Assistance Programs (ADAP). Cities
> and states should be given increased flexibility to use CARE Act funds to
> best meet the health care needs of individuals within their jurisdictions.

> And because we want to maximize the amount of our federal commitment that
> goes directly to those affected, we need to simplify grant applications
> and reduce unnecessary paperwork that consumers the time, money and
> resources of those who are on the front lines of the epidemic.
>
> At the same time, we need to ensure that federal funds reach those
> for who it is intended for- those affected by HIV/AIDS. According to the
> Office of Special Investigations of the General Accounting Office, the
> Ryan White CARE Act is "ripe" for fraud and abuse.
>
> In Puerto Rico, $2.2 million of federal AIDS funds were found to be
> defrauded. More than ten people have been convicted in this case already
> and the investigation is ongoing. This money- intended for those living
> with HIV/AIDS- was instead spent on political campaigns, bribes and
> personal uses. This is not an isolated incident as there have been
> several similar high profile cases during recent years in Florida, North
> Carolina and Texas.
>
> An audit in California found that mismanagement at the Los Angeles
> County AIDS program led to over a half million dollars being spent on
> employees who didn't provide AIDS services and ineffective monitoring of
> other federally funded programs. The audit found that the county AIDS
> office monitored only 13 of the 241 contracts it awards each year to
> groups providing $74 million worth of care and services. More than
> two-thirds of the contractors reviewed by the auditors provided services
> "at levels below contractual requirements." In one case, a contractor
> was paid $90,000 annually to treat 400 adolescent clients, but had
> provided services to only 10 during the first five months.
>
> While these deplorable incidents do not reflect the vast majority of
> the good intentioned and dedicated organizations and individuals receiving
> federal support to provide HIV/AIDS care, the amount of money that has
> been stolen and misused is alarming. It is particularly unfortunate when
> we consider the impact in human terms. How many more patients could have
> been cared for with this money? How many more states with budget
> constraints could have expanded their drug assistance programs ? How many
> more lives could have been saved?
>
> All in all, I believe we have two underlying goals for the Ryan
> White CARE Act. We must first make prevention the priority. Even one new
> case of HIV that could have been prevented is unacceptable.
> Forty-thousand more new infections this year is a failure. Second, we
> must ensure that we do not leave anyone behind by focusing on only AIDS
> and ignoring those with HIV. Such shortsightedness has left many
> communities unprepared for the devastation that they now confront. We must
> be sure they no longer have to face these challenges alone.
>
> Thank you again for the opportunity to testify. I look forward to
> working with all of you to update and reauthorize this very important
> program.

Testimony by

Sandra Thurman

Director, Office of National AIDS Policy

Before the

Senate Committee on Health, Education, Labor, and Pension (HELP)

March 2, 2000

Chairman Jeffords, Senator Kennedy, and Members of the Committee. It is with mixed emotions that I appear before you today. More than ten years ago – when we embarked on this journey together – we had all hoped that this hearing would not be necessary. We yearned to believe that a decade of slow but steady progress would produce a cure or a vaccine – or that effective prevention efforts would reduce the rate of new infections to nearly none. But the fact of the matter is – that while we have much to celebrate today – our Surgeon General has just reminded us that the AIDS pandemic is far from over. And in many ways – our job now grows more difficult, as HIV/AIDS moves most rapidly among traditionally hard to reach populations – women, young people, people of color, and the poor.

HIV and AIDS has touched communities in each and every state across this country. And in big cities and rural towns – AIDS continues to devastate individuals, families, and communities, leaving them impoverished, suffering and in dire need of medical care and support. It is for this reason – and a host of others – that I come to offer the strongest possible support from the President and the Administration for this Committee's bipartisan effort to reauthorize the Ryan White CARE Act.

Since its inception, the CARE Act has literally been a lifeline for hundreds of thousands of Americans in need. And over the years I have had the privilege to witness its programs at work from a variety of different vantagepoints. As the executive director of AID Atlanta, the oldest and largest AIDS service organization in the South, I was honored to work with this Committee in 1989 on the development of this vitally important legislation. As a recipient of Title 1 and Title 2 CARE Act funds, I was proud to testify before this Committee in 1993 on the

successes already taking hold as a result of your thoughtful action. And now, as director of the White House Office of National AIDS Policy, I am pleased to be able to come before you again as we chart our course forward – one which seeks to make this great effort even better.

The CARE Act has become a model for health care delivery not only in the United States, but around the world. It is a shining example of the good that can come from collaboration, coordination, and concerted action. The CARE Act has brought together Republicans and Democrats, cities and states, hospitals and community-based organizations, providers and people living with AIDS – and the results are a tribute to the power of public-private partnerships. It has created a continuum of care that is both compassionate and cost-effective – one that saves both lives and money.

The CARE Act, taken as a whole, stitches together a tapestry of services that enables us to not only respond to locally driven needs – but to reflect the ever-changing face of AIDS.

- **Title 1** focuses on cities hardest hit by this pandemic – providing relief to reduce pressure on already overburdened public health systems and to create community-based and locally controlled systems of care and support for thousands of individuals and families. When the CARE Act was first passed there were 16 such hard hit cities. Today there are 51;
- **Title 2** acknowledges that AIDS knows no geographic boundaries. This title has enabled <u>all</u> states to develop consortia or systems of care, to provide private health insurance, and to expand access to essential drug therapies.

- **Title 3** helps to make primary care and early intervention services available to particularly disenfranchised populations in both rural and urban communities in cooperation with health centers, hospitals, and health departments;
- **Title 4** focuses much needed attention on the unique care and support needs of women, children, and families; and,
- **Title 5** allows for special projects of national significance, acting as a laboratory for demonstrating new and improved model efforts.

But this Act is so much more than the sum of its parts. As a whole, it serves individuals and families in the most efficient and effective way possible. This is not a one size fits all effort. The CARE Act gives each state and community the flexibility they need to weave together a means of caring for their own in a manner that is tailored to indigenous strengths and circumstances.

When the CARE Act was originally created we were sadly unable to do much for those who were sick – and many of the services provided were designed to help people die with dignity. Thankfully, much has changed. The CARE Act is now solidly about <u>living</u> with HIV and AIDS. Since the last reauthorization, biomedical research has brought hope and renewed optimism with the discovery of protease inhibitors and combination therapies. But without the CARE Act, these cutting-edge therapies would have been about as meaningful to many in Selma or the South Bronx as they currently are in South Africa. The CARE Act has made the promise of biomedical research a reality in the lives of people living with HIV and AIDS in every corner of this country.

Last year alone, approximately one hundred thousand people living with HIV and AIDS received access to drug therapy because of the CARE Act. This is particularly important given that half of the people served by the Act have family incomes of less than $10,000 a year – and the new drug "cocktails" cost more than $12,000 annually. And we know all too well, that the drugs alone are not enough. Primary care and support services are vital to ensuring both access and adherence to these complex drug regimens. It is this comprehensive package of essential services that the CARE Act provides – and with impressive results.

The CARE Act has helped to:

- reduce both the frequency and length of expensive in-patient hospitalizations by at least 30%;
- reduce AIDS mortality by 70%;
- reduce mother-to-child transmission of HIV by 75%; and,
- enhance both the length and quality of life for people living with AIDS.

According to a study done by the National Center for Health Statistics, between 1995 and 1997, the nation has seen a 30% decline in HIV related hospitalizations – resulting in nearly one million fewer HIV related hospital days. This represents a saving of more than $1 billion – money much more effectively invested in enabling people with HIV to live healthier and more productive lives. These positive outcomes highlight why the Ryan White CARE Act reauthorization is so imperative.

We stand at a critical juncture in this pandemic – and we must be sure that the success of the CARE Act does not breed complacency but constructive action. Increasingly, the AIDS epidemic in the United States parallels the pandemic globally – with more and more disenfranchised people caught in the crossfire.

Last year, the CARE Act served an estimated half million people living with HIV and AIDS – and affected the lives of millions more. Nearly 6 in 10 of these people were poor. They were also five times more likely to be uninsured than those receiving care elsewhere, nearly 3 times more likely to be African American, and 50% more likely to be women. Clearly the CARE Act has followed the path paved by this epidemic – but challenges remain as HIV and AIDS moves deeper into underserved communities already plagued by poverty, homelessness, and substance abuse, and as treatment demands and costs continue to rise.

I am heartened to see that the Committee's bipartisan reauthorization effort currently being developed is designed to retool and upgrade existing CARE Act mechanisms to:

- expand access to essential services, particularly for vulnerable populations;
- improve the quality of care; and,
- increase the accountability of the overall program.

Surgeon General Satcher has talked at length about existing health disparities – and this Administration is firmly committed to moving on multiple fronts to eliminate these disparities. Certainly, the CARE Act has a vitally important role to play in that effort.

I applaud the Committee for moving forward with proposals which:

- increase program planning and responsiveness;
- create better CARE Act provider linkages with emergency rooms, drug treatment programs and other places that people in need may enter a system of care – and with Medicaid, CHIP, and other potential payers;
- develop capacity to deliver essential services in hard to reach rural and urban areas;
- create an incentive fund in the drug reimbursement program to help remove existing barriers to drug therapy; and,
- move toward a more performance based – outcome oriented system.

I believe that these program enhancements – built on the CARE Act's firm foundation will lead this vital effort – and the millions whose lives depend on it -- safely into the future. We in the Administration look forward to working closely with all of you to secure the swift reauthorization of this landmark legislation.

In 1990, shortly after Ryan White's death, this Committee chose to build a legacy in his name. In so doing, the Committee Report read: "By dedicating this legislation to Ryan, the Committee affirms its commitment to provide care, compassion, and understanding to people with AIDS everywhere. Ryan would have expected no less." Mr. Chairman and Members of the Committee – Ryan White changed our world – and so has your gift in his name.

As the Reverend Dr. Martin Luther King, Jr. once said: "Everybody can be great, because anybody can serve. You don't have to know about Plato and Aristotle to serve. You don't have to know Einstein's theory of relativity to serve. You don't need to know the second theory of thermodynamics to serve. You only need a heart full of grace and a soul generated by love."

Mr. Chairman, this Committee has demonstrated a heart full of grace in formulating, passing, and now sustaining the Ryan White CARE Act. It is an act of service – to people living with HIV and AIDS, to all-enduring American family values, and to good government at its best.

Thank you very much.

MASTER COPY

Testimony by

Sandra Thurman

Director, Office of National AIDS Policy

Before the

Senate Committee on Health, Education, Labor, and Pension (HELP)

March 2, 2000

A safe and effective vaccine is a critical missing element in our fight against this AIDS pandemic. However, three years ago the President challenged the Nation to develop an AIDS vaccine. The National Institutes of Health have moved forward aggressively, consistent with that challenge, to stimulate research toward that end.

Chairman Jeffords, Senator Kennedy, and Members of the Committee. It is with mixed emotions that I appear before you today. More than ten years ago -- when we embarked on this journey together – we had all hoped that this hearing would not be necessary. We yearned to believe that a decade of slow but steady progress would produce a cure or a vaccine – or that effective prevention efforts would reduce the rate of new infections to nearly none. But the fact of the matter is – that while we have much to celebrate today – our Surgeon General has just reminded us that the AIDS pandemic is far from over. ~~In fact, with no vaccine or cure in sight, we are closer to the beginning of this epidemic than we are to the end~~. And in many ways – our job now grows more difficult, as HIV/AIDS moves most rapidly among traditionally hard to reach populations -- women, young people, people of color, and the poor.

HIV and AIDS has touched communities in each and every state across this country. And in big cities and rural towns – AIDS continues to devastate individuals, families, and communities, leaving them impoverished, suffering and in dire need of medical care and support. It is for this reason -- and a host of others -- that I come to offer the strongest possible support from the President and the Administration for this Committee's bipartisan effort to reauthorize the Ryan White CARE Act.

Since its inception, the Ryan White CARE Act has ~~literally been a lifeline for millions of~~ supplied medical and support services to hundreds of thousands of ~~young~~ Americans in need. And over the years I have had the privilege to witness the CARE Act at work from a variety of different vantagepoints. As the executive director of AID Atlanta, the

oldest and largest AIDS service organization in the South, I was honored to work with this Committee in 1989 on the development of this vitally important legislation. As a recipient of Title 1 and Title 2 Ryan White funds, I was proud to testify before this Committee in 1993 on the successes already taking hold as a result of your thoughtful action. And now, as director of the White House Office of National AIDS Policy, I am pleased to be able to come before you again as we chart our course forward – one which seeks to make this great effort even better.

The CARE Act has become a model for health care delivery not only in the United States, but around the world. It is a shining example of the good that can come from collaboration, coordination, and concerted action. The CARE Act has brought together Republicans and Democrats, cities and states, hospitals and community-based organizations, providers and people living with AIDS – and the results are a tribute to the power of public-private partnerships. It created a continuum of care that is both compassionate and cost-effective – one that saves both lives and money.

The CARE Act, taken as a whole, stitches together a tapestry of services that enables us to not only respond to locally driven needs – but to reflect the changing face of AIDS.

- **Title 1** focuses on cities hardest hit by this pandemic – providing "~~disaster~~ relief" ✓ to reduce pressure on already overburdened public health systems and to create community-based and locally controlled systems of care and support for thousands of individuals and families. When the CARE Act was first passed there were 16 such hard hit cities. Today there are 51;

- **Title 2** acknowledges that AIDS knows no geographic boundaries. This title has enabled all states to develop consortia or systems of care, to provide private health insurance, and to expand access to essential drug therapies.
- **Title 3** helps to make primary care and early intervention services available to particularly disenfranchised populations in both rural and urban communities in cooperation with health centers, hospitals, and health departments;
- **Title 4** focuses much needed attention on the unique care and support needs of women, children, and families; and,
- **Title 5** allows for special projects of national significance, acting as a laboratory for demonstrating new and improved model efforts.

But this Act is so much more than the sum of its parts. As a whole, it serves individuals and families in the most efficient and effective way possible. This is not a one size fits all effort. The CARE Act allows each state and community the flexibility to weave together a means of caring for their own in a manner that is tailored to indigenous strengths and circumstances.

When the CARE Act was originally created we were sadly unable to do much for those who were sick – and many of the services provided were designed to help people die with dignity. Thankfully, much has changed. The CARE Act is now solidly about living with HIV and AIDS. Since the last reauthorization, biomedical research has brought hope and renewed optimism through the discovery of protease inhibitors and combination therapies. But without the CARE Act, these cutting-edge therapies would have been about as meaningful to many in

Selma or the South Bronx as they currently are in South Africa. The CARE Act has made the promise of biomedical research a reality in the lives of people living with HIV and AIDS in every corner of this country.

Last year alone, ~~more than~~ approximately one hundred thousand people living with HIV and AIDS received ~~their~~ access to drug therapy because of the CARE Act. This is particularly important given that half of the people served by the Act have family incomes of less than $10,000 a year – and the new drug "cocktails" cost more than $12,000 annually. And we know, that the drugs alone are not enough. Primary care and support services are vital to ensuring both access and adherence to complex drug regimens. It is this comprehensive package of essential services that the CARE Act provides – and with impressive results.

The CARE Act has helped to:

- reduce both the frequency and length of expensive in-patient hospitalizations by at least 30%;
- reduce AIDS mortality by 70%;
- reduce mother-to-child transmission of HIV by 65%; and,
- enhance both the length and quality of life for people living with AIDS.

According to a study done by the National Center for Health Statistics, between 1995 and 1997, the nation saw a 30% decline in HIV related hospitalizations – resulting in nearly one million (900,000) fewer HIV related hospital days. This represents a saving of more than $1

billion – money much more effectively invested in enabling people with HIV to live healthier and more productive lives. That is why the Ryan White CARE Act reauthorization is so imperative.

We stand at a critical juncture in this pandemic. And we must be sure that the success of the CARE Act does not breed complacency but constructive action. Increasingly, the AIDS epidemic in the United States parallels the pandemic globally – with more and more disenfranchised people caught in the crossfire.

Last year, the CARE Act served ~~nearly a~~ an estimated half million people living with HIV and AIDS – and affected the lives of millions more. Nearly 6 in 10 of these people were poor. They were also five times more likely to be uninsured than those receiving care elsewhere, nearly 3 times more likely to be African American, and 50% more likely to be women. Clearly the CARE Act services have followed the path paved by this epidemic – but challenges remain as HIV and AIDS moves deeper into underserved communities and as treatment costs continue to rise.

I am heartened to see that the Committee's bipartisan reauthorization effort currently being developed is designed to retool and upgrade existing CARE Act mechanisms to:

- expand access to essential services, particularly for vulnerable populations;
- improve the quality of care; and,
- increase the accountability of the overall program.

Surgeon General Satcher has talked at length about existing health disparities – and this

Administration is firmly committed to moving on multiple fronts to eliminate these disparities. Certainly, the CARE Act has a vitally important role to play in this effort. I applaud the Committee for moving forward with those provisions which:

- increase program planning and responsiveness;
- create better CARE Act provider linkages with emergency rooms, drug treatment programs and other places that people in need may enter a system of care – and with Medicaid, CHIP, and other potential payers;
- ~~further target new money;~~
- develop capacity to deliver essential services in hard to reach rural and urban areas;
- create an incentive funds in the drug reimbursement program to help remove existing barriers to drug therapy; and,
- move toward a more performance based – outcome oriented system.
- prioritize medical services while recognizing the value of wrap-around, support services

I believe that these program enhancements – built on the CARE Act's strong foundation will lead this vital effort and the millions of whose lives depend on it safely into the future. We in the Administration look forward to closely working with you – on a solidly bipartisan basis -- to secure the reauthorization of this landmark legislation.

In 1990, shortly after Ryan White's death, this Committee chose to build a legacy in his name. In so doing, the Committee Report read: "By dedicating this legislation to Ryan, the Committee affirms its commitment to provide, care, compassion, and understanding to people

with AIDS everywhere. Ryan would have expected no less." Mr. Chairman and Members of the Committee – Ryan White changed our world – and so has your gift in his name.

As my hometown preacher from Atlanta, the Reverend Dr. Martin Luther King, Jr. once said: "Everybody can be great, because anybody can serve. You don't have to know about Plato and Aristotle to serve. You don't have to know Einstein's theory of relativity to serve. You don't to know the second theory of thermodynamics to serve. You only need a heart full of grace and a soul generated by love."

Mr. Chairman, this Committee has demonstrated a heart full of grace in formulating, passing, and now sustaining the Ryan White CARE Act. It is act of service – to people living with HIV and AIDS, to all-American family values, and to government at its best.

Thank you very much.

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Testimony for David Satcher, M.D., Ph.D.
Senate Health, Education, Labor and Pensions Committee
Hearing on Ryan White CARE Act Reauthorization
March 2, 2000

Introduction

Thank you for this opportunity to speak before you at this important hearing on the Ryan White CARE Act as you consider the reauthorization of this program. The CARE Act, as it is called in brief, has been a cornerstone of our public health response to the HIV/AIDS epidemic in this country since 1990, taking effect in a time when hospitals and emergency rooms were struggling to take care of ever increasing numbers of people critically ill and dying from AIDS. Since those days, the steadying effect of developing a network of community-based health and social services, and the advent and availability of effective treatments through the Ryan White CARE Act, has led to more individuals living longer and healthier lives as productive members of their communities.

As we witness the dramatic changes taking place in other nations of the world now confronting exploding epidemics of HIV/AIDS, we recognize that the course of the HIV epidemic in the United States is also changing. The hope and promise of effective treatment is balanced by sobering realities that the HIV epidemic is increasingly affecting members of racial and ethnic minority communities, as well as vulnerable groups such as youth, those struggling with substance abuse addictions, mental illness, homelessness, the poor and those who are uninsured or underinsured. We face the challenges of caring for an ever increasing number of individuals living with HIV disease - a disease with no cure in sight – for which the treatment regimens are complicated and costly.

In this changing environment, the Ryan White CARE Act is more important than ever. The availability of quality primary care and the services needed to adhere to difficult treatment regimens is essential, if we are to continue to make progress against this relentless disease. While our prevention efforts are geared to reducing new infections, those living with the disease must be embraced in appropriate, quality care and services that have proven to be lifesaving and cost-effective. To ensure this, the reauthorization of the Ryan White CARE Act is one of the Department's top legislative priorities for Fiscal Year 2000.

Today I would like to offer you a brief overview of the HIV/AIDS epidemic in the United States, as it is affecting individuals, communities, and the systems of care designed to serve them. This is followed by a discussion of the Ryan White CARE Act programs and the role these play in providing essential services to persons living with HIV/AIDS. Finally, I'd like to address some of

the challenges that the Department is working to address as we continue to refine and improve our ability to provide high quality services to all people living with HIV disease who need this assistance.

Overview of the Epidemic

The HIV/AIDS epidemic has taken a heavy toll on the United States since it was first identified in 1981. Over 688,000 Americans have been diagnosed with AIDS, and more than 410,000 men, women and children have lost their lives to this disease. The Centers for Disease Control and Prevention has estimated that between 625,000 and 900,000 individuals are living with HIV/AIDS in the U.S. today. The number of new AIDS cases reported each year has been sloping downward, with 47,887 new cases reported to the CDC in 1998. However, AIDS cases no longer serve as a close surrogate for the numbers of individuals who need medical care and services, as appropriate care and effective therapies can now extend the years of productive life with HIV disease.

In recent years, estimates of the number of new HIV infections occurring each year have stabilized around 40,000. Within the last four years, there have been dramatic declines in the numbers of deaths due to AIDS, due in large part to effective antiretroviral therapies and access to health care services such as those supported through the Ryan White CARE Act programs. In 1998, approximately 17,100 persons died of AIDS. It is important to note that these reductions in death rates have not been achieved equally across all racial and ethnic groups – as AIDS remains the leading cause of death among African Americans 25-44 years of age despite its national ranking as the 14 leading cause of death. However, putting other factors aside for the moment, the math is quite straightforward and simple – more people are living with HIV/AIDS for longer periods, increasing the overall demand for medical care and those services needed to access and benefit from that care.

It is very clear that the numbers alone do not tell the story of the impact of HIV/AIDS on our communities and health care systems. The demographics of the epidemic have been steadily changing, with the majority of new AIDS cases reported among racial and ethnic minority populations, and groups that traditionally have faced many barriers to accessing health care services. In 1998, white Americans who account for 73 percent of the U.S. population represented 34 percent of newly reported AIDS cases. By comparison, African Americans who comprise 12 percent of the population accounted for 45 percent of new AIDS cases, and 60 percent of new AIDS cases among women. Persons of Hispanic descent were also disproportionately impacted, accounting for 20 percent of new AIDS cases compared to their 10.8 percent representation in the population.

A closer look at who is being affected by HIV shows that the proportion of new AIDS cases occurring among women, and new HIV infections among youth, are increasing. Women accounted for 23 percent of new AIDS cases in 1998, with 80 percent among racial minorities. Two of every three women living with HIV disease are believed to be mothers of at least one child less than 19 years of age, extending the impact of this disease to their children. Youth are also at risk for, and increasingly affected by, HIV/AIDS. As many as half of all new infections

are occurring in people under the age of 25, and one quarter of all new HIV infections occur in persons under the age of 22 years. This population presents special challenges, as individuals may live without symptoms for years. When adolescents and youth become ill, they are more likely to be uninsured without ongoing health care and to use systems in an episodic manner.

The impact of the HIV epidemic on communities and systems of care is also affected by the large numbers of persons infected through substance abuse – particularly injection drug use – and those living with other concurrent medical and social problems such as mental illness, homelessness, and poverty. Forty three percent of cumulative AIDS cases among women, and twenty two percent among men, are attributed to injection drug use. The presence of comorbidities such as substance abuse addiction and mental illness impacts an individual's ability to make healthy decisions, access health services, and comply with treatment regimens. These present unique challenges to the delivery of ongoing quality medical care and prevention interventions.

General Trends in HIV/AIDS Care

Financing As with other diseases, the health care system for the delivery of HIV/AIDS care comprises a mix of public and private financing sources and care delivery systems. However, HIV/AIDS disproportionately strikes individuals who are poor and under or uninsured and a greater proportion of persons newly infected with HIV or recently diagnosed with AIDS rely on publically supported health care programs.

In 1998, results from a study of a nationally representative sample of HIV-positive adults receiving medical care in the United States [the HIV Cost and Services Utilization Study (HCSUS)] were published in the New England Journal of Medicine. This study found that 20 percent of persons had no public or private insurance, 29 percent were enrolled in Medicaid, and 32 percent had private insurance. The HCSUS data for 1996 found that the annual household incomes of seventy two percent of HIV-infected adults was less than $25,000, with forty six percent of households below an annual income of $10,000. A second analysis conducted on the HCSUS data base comparing the patient characteristics of CARE Act providers compared to non-CARE Act providers found that CARE Act providers were more likely to treat persons who have no public or private health insurance [28% vs. 6%], who are of racial minority [60% vs. 38%], are women [26% vs 18%], have not completed high school [39% vs. 19%], and have annual incomes less than $10,000 [55% vs. 34%].

Currently the Medicaid program is the largest public payor (paying approximately $3.9 billion) for HIV/AIDS care, with Medicare as the second largest payor with $1.5 billion in FY99. Up to half of all individuals with an AIDS diagnosis are receiving care under the Medicaid program. Adults with HIV infection do not usually become eligible for Medicaid until they become disabled by their HIV disease (usually concurrent with an AIDS diagnosis), unless they qualify under alternative eligibility criteria (e.g. pregnant women with children). Current guidelines for the treatment of HIV infection recommend initiating antiretroviral drugs at an earlier stage of disease prior to the profound compromise of the immune system which is the hallmark of full blown AIDS. Expenditures in the Medicare program have been increasing by

between $100 million to$200 million annually over the last 5 years as the AIDS disabled population has lived longer with new treatments.

The Ryan White CARE Act Programs provided nearly 25 percent of the Federal funding for the delivery of HIV-related health care services. The majority of these funds – 64 percent in 1998 – were used for medical care and treatment. An additional 23 percent were used to fund support services that improve coordination of care and increase the ability of individuals to access care and benefit from medical management and treatment.

Estimated Numbers in Care The HCSUS study also estimated that 335,000 persons with HIV disease were receiving at least some health care for their HIV disease in 1996. For this same time, the CDC estimated the prevalence of HIV/AIDS to be between 650,000 to 900,000 persons, of whom an estimated 550,000 persons were aware of their HIV positive status. Using these estimates, approximately 215,000 may be aware of their HIV status but not seeking care for their illness. The reasons for this are not well characterized by systematic research, and may range widely from lack of understanding of HIV and medical interventions, fear of disclosing HIV status, lack of access to culturally sensitive care, barriers in accessing necessary ancillary services such as mental health and substance abuse services, child care, case management, transportation, and others.

Patterns in Care The medical management of HIV disease has changed significantly with the advent of multiple effective antiretroviral medications, in particular the discovery of the class of drugs known as protease inhibitors. Unlike the years prior to 1995, when the primary therapeutic tools were treatment for opportunistic infections and the benefits of antiretrovirals were yet under study, there are now 14 approved antiretroviral drugs for the treatment of HIV/AIDS. Now there are countless examples of individuals, once desperately ill, regaining their health and returning to work. Rates of inpatient hospitalization have plummeted, and deaths due to AIDS have declined sharply.

The U.S. Public Health Service has issued recommended treatment guidelines for the use of antiretretroviral medications for HIV-infected adults and adolescents, for pediatric HIV/AIDS, and for the reduction of perinatal HIV transmission and treatment of maternal HIV disease. New knowledge about the emergence of resistance to specific drug combinations, combined with laboratory monitoring techniques to assess extent and progression of disease, has made the medical management of HIV increasingly complex, particularly for primary care providers without specific training in HIV.

A critical factor in the success of any antiretroviral regimen is the ability of the person with HIV disease to adhere to the dosing schedules and dietary restrictions recommended for that regimen, in order to maximize the drug benefit and minimize the emergence of drug resistance. Certain medications require refrigeration. Others have distressing side effects so severe that clients need assistance to manage them, or find the regimen intolerable. These therapeutic challenges often necessitate a range of support services from Ryan White CARE Act providers, especially for populations also addressing issues of substance abuse, homelessness, and poverty.

Costs of Care

Pressure on the Ryan White CARE Act funds has increased in recent years because of the changing paradigm beneath HIV/AIDS treatment costs: while the number and duration of hospitalizations has fallen, outpatient costs have risen sharply and will continue to do so for the foreseeable future with greater numbers of individuals living with HIV disease for longer periods. Moreover, a growing proportion of those living with HIV/AIDS are women, youth, and minorities -- populations that have historically lacked private health insurance and who are more likely to have other medical problems in addition to HIV infection. However, no issue has been a greater factor in rising outpatient costs than highly active antiretroviral therapy (HAART).

People living with HIV disease are living longer, as a benefit of HAART, and are turning to CARE Act providers for clinical and other services in increasing numbers, even as the number of new AIDS cases drops. The annual costs of HAART can be $12,000 or higher, in addition to other health care costs associated with treating HIV disease, also requiring specialists educated and experienced in the challengesof administering HAART and treating illnesses common among HIV-positive persons.

The demand for HAART medications, and the clinical and laboratory monitoring associated with these, has grown dramatically. Between 1996 and 1999, enrollment in Ryan White funded AIDS Drug Assistance Programs (ADAPs) increased by nearly 40,000 individuals, a 53 percent increase. These individuals are remaining on ADAP rolls for longer periods of time as the transition to Medicaid becomes more difficult. Not all people with HIV disease will choose to use combination therapy. However, with continued improvement in treatment options and the PHS antiretroviral guidelines recommending earlier intervention with combination therapy, the number of people seeking to learn their status, entering primary care, and seeking clinically appropriate access to pharmaceutical treatment has increased over time.

Projecting the future costs of ADAP programs has been difficult. Some State ADAPs report limited formularies, waiting lists, and more restricted access to specific drugs on formularies because of increased demand on their programs. In 1999, 22 States were unable to cover persons with income levels above 200 percent of Federal poverty level. Seven States continue to place restrictions on their ADAP formularies. It is clear that significant demand exists for both prescription drugs and underlying primary care services necessary to deliver the treatments.

Disparities in Health Outcomes The disparities noted earlier in terms of unequal reductions in the death rates due to HIV/AIDS among racial and ethnic populations are observed earlier in the treatment setting. The HCSUS study clearly demonstrated that, although improvements in care could be documented, disparities continue to exist between certain groups in their ability to access and receive quality care for their HIV disease. Individuals from racial and ethnic minority groups, women, and the uninsured of all ages were among those most likely to receive inadequate or inappropriate care, as evidenced by appropriate selection of antiretroviral treatments and prophylaxis for opportunistic infections. There are many possible contributing factors to these findings, including lack of provider expertise in the management of HIV disease, fiscal barriers to receipt of services or medications, individual circumstances of dual diagnoses of

mental illness or susbtance abuse, and unstable housing which may affect the provider's willingness to prescribe HAART, among others. Support services often play an essential role in enabling individuals to access and remain in care and achieve better health outcomes. Identifying and addressing the contributing factors within the health care setting that lead to unequal and suboptimal care and health outcomes will be a critical activity throughout all the Ryan White CARE Act programs this year and in the future.

The Role of the Ryan White CARE Act Program

The Ryan White CARE Act has played a central role in the public health response to the HIV/AIDS epidemic. It has been very clear that we are not going to get ahead of this epidemic unless we are able to reach out, engage and enter people living with the disease into systems of health care and support services . Even as our systems for HIV prevention reach out and work to reduce the number of new HIV infections, our ability to curtail the epidemic is directly related to the ability to enter and retain affected persons in systems of care.

A hallmark of the Ryan White CARE Act programs has been the provision of essential health and social services to persons and families experiencing serious levels of medical and social service needs related to HIV disease who have few, if any, resources of their own. For many, the Ryan White CARE Act has become the final safety net for essential HIV-related services. The CARE Act has afforded the ability to develop flexible systems of community-based care, responsive to the local demographics and institutions through which to deliver care and services. As the demographics of the epidemic move increasingly into more disenfranchised populations, the importance of a community-based response able to interface with and respond to vulnerable populations increases.

The basic structure of the CARE Act has been extremely durable over time. Title I has provided urgent assistance to Eligible Metropolitan Areas (EMAs) with over 2000 living AIDS cases . The Title II program has provided funds to States to improve the quality, availability, and organization of HIV/AIDS health care and support services, and to provide access to costly pharmaceuticals through the AIDS Drug Assistance Program (ADAP). Title III supports outpatient comprehensive HIV care, including early intervention services, for low income, medically underserved individuals and has assisted in the development of new capacity for these services in rural and underserved areas through planning grants. Title IV provides comprehensive, community-based, family-centered services to children, youth and women living with HIV and their families, and facilitates access of these populations to clinical trials. The AIDS Education and Training Centers (AETC) Program supports education and training of health care providers who counsel, diagnose, treat and manage care for individuals with HIV infection and to help prevent high risk behaviors that cause infection. The Special Projects of National Significance (SPNS) program supports the development and evaluation of innovative HIV/AIDS service delivery models that have potential for replication, locally and nationally. Finally, the
HIV/AIDS Dental Reimbursement Program assists accredited dental schools and postdoctoral dental education programs with uncompensated costs incurred in providing oral health treatment to patients with HIV disease.

The Ryan White CARE Act Programs have continued to serve growing numbers of individuals with HIV/AIDS. An estimated 500,000 clients were served through Titles I and II in 1997, including 110,000 individuals receiving assistance in accessing medications for their HIV disease. The majority of these services were received by persons of racial and ethnic minorities (in Title I, African Americans 45%, Hispanic 21%; Title II - African American 43%, Hispanic 19%; Title III - African American 31%, Hispanic 23%; Title IV - African American 58%, Hispanic 23%).

The trends of how these resources are spent across categories of services has changed over time, reflecting in part the benefits of new therapies and increased need for support services linked with
primary medical care as the epidemic has moved into more vulnerable and marginalized populations. Between 1996 and 1999, the following changes in expenditures for specific services were reported:

* 14.8% decline in hospice care
* 28.4 percent decline in day/respite care
* 57 percent decline in home and community care (Title II program)
* 62.4 percent decline in rehabilitation services
* 5.2 percent increase ($10 million) in substance abuse counseling and treatment
* 8.4 percent increase ($46 million) in medical/dental treatment
* 16.2 percent increase ($6 million) in client advocacy
* 22.1 percent increase ($11 million) in nutrition/food services
* 28.6 percent increase ($6 million) in emergency assistance

Additional information specific to each of the Ryan White CARE Act programs is provided as a reference in the Appendix.

Challenges for the Future

The Ryan White CARE Act has been widely successful across this country in reaching out and providing essential health care services to people living with HIV/AIDS. The measures of progress are visible, in dropping death rates, dramatic declines in inpatient hospitalization, and individuals regaining better levels of health and able to return to work and community activities. At the same time, there are clear signs that all people living with HIV are not benefitting equally from these advances in treatment and care. Now, with effective and life-prolonging new treatments available, a strong focus must be placed on ensuring all individuals living with HIV disease are embraced in systems of quality medical care, with access to lifesaving therapies and those support services necessary to realize their benefit.

As this Committee moves forward to consider the reauthorization of the Ryan White CARE Act, the Department is recommending several modest legislative changes to the existing law designed to improve and expand access to care, increase accountability, and enhance service capacity in underserved urban and rural communities. Each of these legislative recommendations is described below:

Increase Access to Care for Vulnerable Populations

- HHS shall work with title I planning councils, States, and experts in the field to develop and implement activities including: estimates of the number of HIV-infected individuals in the region covered by the grant (including persons not currently receiving HIV-related health care, including women and including persons with addictive disorders); conduct needs-assessment activities among population with HIV disease in the community, including those not in care, in order to establish service needs; and application of such estimates and needs-assessment information in planning for services.

- Grantees under titles I and II shall develop strategies for maximing use of Medicaid and State Children's Health Insurance Programs funds to cover HIV-related health care costs of eligible individuals when planning for services and allocating funds.

- Grantees shall establish referral relationships between Ryan White providers and other health care providers that serve as key points of access to the health care system, for example, emergency rooms, family planning clinics, substance abuse treatment facilities, adult and juvenile detention centers, and others.

- Allow use of titles I and II funds for early intervention services at key points of entry to the health care system and among Ryan White service programs for purposed of identifying persons needing HIV care and bringing them into care, where no other Federal, State, or local funds are available.

- Expand eligibility of the Dental Reimbursement Program to include community health centers in order to expand services to smaller metropolitan and rural areas.

- Implement a title II AIDS Drug Assistance Program (ADAP) supplemental award to target additional funds to States with demonstrated need for HIV-related treatments.

Assess and Improve Quality of Services

- HHS shall work with Title I Planning Councils, States, and experts in the filed to develop and implement a quality management program for all grantees in order to develop performance measures, establish an assessment process, and use information to improve the quality of medical and support services.

- HHS shall provide additional resources to grantees for quality management programs.

- Ensure that social support services funded under the Act shall be related to improved access to health services and outcomes.

Capacity Development

- Enhance EMA and State activities under Titles I and II related to assessing needs for and implementing capacity development activities for low-income, historically underserved communities, in order to promote access to primary care services.

- Expand Title III planning grants activities to include capacity development grants of upto $150,000 for a period of up to 3 years to enhance the delivery and benefits of HIV primary care services to low-income, historically underserved communities.

Comprehensive Study of Financing and Development of HIV Services

- HHS shall request a study of the delivery and financing of HIV services among low-income, under and uninsured individuals with HIV disease conducted by the National Academy of Sciences Institute of Medicine.

- The purpose of the study is to examine key factors with the effective and efficient financing and delivery of HIV services. We expect that the study would include CARE Act financing of services in relation to the existing public (e.g. Medicaid, Medicare) and private health services, general demographics (race/ethnicity, poverty, age urban/rural, etc.) and co-morbidities (substance abuse, mental health, homelessness) of members, regional variations in the funding and costs of delivery services, and available epidemiologic tools and data sets necessary for local and national resource planning and allocation decisions.

Other Recommendations

- Continue the Title IV relationship with research programs but remove requirements related to enrollments in clinical trials.

- Increase Title III administrative cap and establish Title IV administration cap.

The Department stands ready to be of assistance to this Committee and Congress to achieve the important goal of reauthorizing the Ryan White CARE Act this year. Thank you for your commitment and vision to keep the hope of this vital program alive for the thousands of Americans whose lives depend on it.

APPENDIX

Ryan White CARE Act Program Descriptions

The Ryan White CARE Act was first enacted on August 18, 1990 and reauthorized on May 20, 1996 to improve the quality and availability of care for low-income, uninsured, and underinsured individuals and families affected by HIV disease. Since FY 1991, more than $7.950 billion in Federal funds has been awarded to all 50 States, the District of Columbia, Puerto Rico, and U.S. territories. The CARE Act is administered by the HIV/AIDS Bureau, Health Resources and Services Administration, Department of Health and Human Services. The CARE Act funds HIV/AIDS health care and support services under four Titles and Part F.

Title I: Emergency Assistance to Eligible Metropolitan Areas (EMAs)

Title I provides emergency relief assistance to Eligible Metropolitan Areas (EMAs) that are disproportionately affected by HIV/AIDS. The FY 2000 appropriation totaled $546.5 million in formula and supplemental funds and was awarded to 51 EMAs.

Eligibility

Title I provides emergency assistance to eligible metropolitan areas (EMAs) most severely affected by the HIV/AIDS epidemic. To be eligible, an area must:

- Have more than 2,000 cumulative AIDS cases reported during the past 5 years; and
- Have a population of at least 500,000. This provision does not apply to any EMA designated and funded prior to FY 1997.

When the first Title I grants were awarded in FY 1991, 16 EMAs were identified. In FY 2000, there are 51 EMAs in 21 States, Puerto Rico, and the District of Columbia.

Title I funding includes formula and supplemental components:

- Formula grants are based on the estimated number of people living with HIV disease in the EMA; and
- Supplemental grants are awarded competitively upon demonstration of severe need and other criteria, including:
- The ability to use funds responsively and cost-effectively;
- Plans to allocate funds in accordance with the local demographics of AIDS; and
- A Planning Council membership emphasizing the affected communities and people living with HIV disease.

Services

- Outpatient health care;
- Support services such as case management, home health and hospice care, housing and transportation assistance, nutrition services, and day or respite care; and
- Inpatient case management services that expedite discharge and prevent unnecessary hospitalization.

Providers may include public or nonprofit entities, although private for-profit entities are eligible only if they are the area's lone provider of quality HIV care.

Administration

Grants are awarded to the Chief Elected Official (CEO) of the city or county that administers the health agency providing services to the greatest number of people living with HIV in the EMA. The CEO usually designates an administrative agent (most often the local health department) to select service providers and administer contracts. The CEO or grantee establishes intergovernmental agreements with other political subdivisions within the EMA that provide HIV services and include 10 percent or more of the EMA's total AIDS cases.

Title I HIV Health Services Planning Councils

The CEO must establish an HIV Health Services Planning Council which will set service priorities for the allocation of funds within the EMA, develop a comprehensive plan, and assess the efficiency of a grantee's administrative mechanism for rapidly allocating funds.

Title II: Grants to States

Title II assists States and eligible U.S. territories in improving the quality, availability, and organization of HIV/AIDS health care and support services, and provides access to high-cost pharmaceuticals through the AIDS Drug Assistance Program (ADAP). The FY 2000 appropriation totaled $824 million, which included $528 million for ADAP funding.

Eligibility

Title II grants are awarded on a formula basis to States, the District of Columbia, Puerto Rico, and eligible U.S. territories to provide health care and support services for people living with HIV disease. Grants are awarded to the State agency—usually the health department—designated by the governor to administer Title II.

States with more than one percent of the total AIDS cases reported nationally during the previous two years must contribute their own resources to match the Federal grant, based on a yearly formula. Under Title II, States receive funds earmarked to support AIDS Drug Assistance Programs (ADAP), in addition to a base award that can also be used for ADAP.

Services

Title II funds may be used to support a wide range of services:

- Home and community-based health care and support services;
- Continuum of health insurance coverage, through either a Health Insurance Continuation Program (HICP) or provision of medical benefits under a health insurance program including high risk pools;
- Pharmaceutical treatments through the ADAP Program;
- HIV care consortia that assess needs, organize and deliver HIV services in consultation with service providers, and contract for services; and
- Direct health and support services.

States are required to spend a portion of their Title II award to provide medications to treat HIV disease, including drugs for the prevention and treatment of opportunistic infections. States also must document their progress in making therapeutics available to people with HIV disease who are eligible for assistance.

Providers may include public or nonprofit entities, although private for-profit entities are eligible only if they are the area's lone provider of quality HIV care.

Administration

Title II Care Consortia

Most States provide services directly and through subcontracts with Title II HIV care consortia. A consortium is an association of public and nonprofit health care and support service providers and community-based organizations that plans, develops, and delivers services for people living with HIV disease.

A consortium must submit an application to the State assuring that it has:

- Conducted a needs assessment;
- Developed a plan and set service priorities to meet identified needs;
- Promoted coordination and integration of community resources, addressing the needs of all affected populations;
- Assured the provision of comprehensive outpatient health and support services; and
- Arranged to evaluate the success and cost-effectiveness of the consortium in responding to service needs.

Statewide Coordinated Statement of Need

States are required to have a process in place that periodically convenes people living with HIV disease, representatives of other CARE Act grantees, providers, and public health agencies to develop a Statewide Coordinated Statement of Need (SCSN).

Title II: AIDS Drug Assistance Programs (ADAPs)

Eligibility

Title II funds the AIDS Drug Assistance Programs (ADAPs) to provide medications to low-income individuals with HIV disease, with limited or no coverage from private insurance or Medicaid, in all 50 States and the District of Columbia, Puerto Rico, the Virgin Islands, and Guam.

States have the authority to establish income and medical eligibility criteria and to determine how drugs are purchased and distributed to clients. States also determine which drugs to include on their formularies.

Because Title II allows States to set income and medical eligibility criteria for ADAPs, there is wide variation in eligibility, reflected in the type and availability of other health care resources for low-income, HIV-positive individuals. Even in States with more generous income eligibility standards, the overwhelming majority of enrolled individuals have incomes below 200 percent of the Federal Poverty Level.

All States require individuals who meet income threshold criteria simply to provide proof of their HIV status. Ten States also require a laboratory test showing a CD4 count of 500 or less, indicating significant damage to the immune system, and eight States have additional criteria to obtain protease inhibitors and/or antiretrovirals.

Services

Title II requires that "A State shall use a portion of the amounts provided to establish a program... to provide therapeutics to treat HIV disease or prevent serious deterioration of health arising from HIV disease in eligible individuals, including measures for the prevention and treatment of opportunistic infections."

ADAPs have served clients since 1987, but recent treatment advances have focused increasing attention on the program. The newest class of HIV drugs, protease inhibitors (PIs), has proven to be very effective when used in combination with two or three other medications. As a result, demand for the promising new combination therapy has grown rapidly, not only among individuals already in care, but also among those who had not previously sought treatment. Because the cost of combination therapy with PIs is very high—between $10,000 and $12,000 a year per person—ADAPs are challenged in responding to the increased client demand.

Even before the expensive new drugs became available, many ADAPs were straining to meet demands. The rapid growth of the HIV epidemic among poor and historically underserved

populations, and evolving treatment standards with multiple antiviral drugs, has contributed to these strains. In addition, the number of people seeking and receiving treatment for HIV and AIDS continues to increase on a monthly basis.

Covered Drugs

As the number of FDA-approved HIV treatments increases, States have added some or all of the newer drugs within their resource limitations. The availability of new, more effective drugs, combined with the increased cost of these medications, has affected the expansion of formularies. Today, there is considerable variation in the number of drugs on ADAP formularies, ranging from 12 to more than 300, with approximately 60 percent of the States covering 30 or more drugs.

Purchase and Distribution of Pharmaceuticals

Most ADAPs were established to operate under a pharmacy reimbursement model similar to Medicaid. Patients fill their prescriptions at participating pharmacies that subsequently bill ADAP. Some States use a system of pharmacies attached to a network of public health clinics to purchase and distribute drugs for ADAP clients. Only a few ADAPs directly purchase drugs and mail them to clients.

Cost-Containment Measures

Because of the significant growth in clients seeking treatment, dramatic increases in the cost of new treatments, and rapidly changing standards of care, ADAPs are looking for new ways to contain costs while expanding access. Some of the methods include:

- Changing the system used to purchase and distribute drugs
- Seeking larger price discounts, for example, by participating in HRSA's Section 340B Drug Discount Program or negotiating voluntary manufacturers' rebates
- Tightening income eligibility criteria
- Deleting some drugs from State formularies
- Setting caps on ADAP benefits
- Establishing guidelines for prescribing drugs

Title III: Early Intervention Services

Title III supports outpatient HIV early intervention services for low-income, medically under served people in existing primary care systems. In FY 2000, Title III was appropriated $138.4 million.

Eligibility

Title III supports comprehensive primary health care and other services for individuals who have been diagnosed with HIV disease. These grants expand the capacity of organizations providing

primary care services to indigent HIV-positive individuals, but generally do not fund many of the support services available through other CARE Act programs

Currently, 189 programs providing early intervention services and 27 communities conducting early intervention planning grants are funded:

- 37 percent are Federally-qualified Community Health Centers and Migrant Health Centers;
- 24 percent are hospital or university-based medical centers;
- 17 percent are city and county health departments; and
- 20 percent are community based health centers that are not federally funded.

Additionally, 2 percent of Title III programs are funded through providers of health care for the homeless, family planning clinics, and comprehensive hemophilia diagnostic and treatment centers.

Services

Title III services include:

- Risk-reduction counseling, partner involvement in risk reduction, education to prevent transmission, antibody testing, medical evaluation, and clinical care;
- Antiretroviral therapies, protection against opportunistic infections, ongoing medical, oral health, nutritional, psychosocial, and other care for HIV infected clients;
- Case management to assure access to services, and continuity of care for HIV infected clients; and
- Addressing "co-epidemics" that occur frequently in association with HIV infection, including tuberculosis and substance abuse.

Title IV: Services for Women, Children and Families

Title IV focuses on providing comprehensive, community-based, and family centered services to children, youth, and women living with HIV and their families. Title IV program services include primary and specialty medical care, psychosocial services, and logistical support, as well as outreach and prevention to provide a continuum of care for at-risk populations. Title IV systems of care enhance access to and linkage with clinical research supported by the National Institutes of Health and other organizations for their client populations.

Clients

In 1997, the organizations receiving Title IV funding reported serving 32,612 clients, of which 16,115 (49 percent) were HIV positive. Of all clients:15 percent were infants; 31 percent were children; 18 percent were adolescents and young adults; 24 percent were adult women; 5 percent were pregnant women; and 7 percent were adult men. The vast majority of Title IV clients are members of racial and ethnic minorities:

- 58 percent of enrolled clients in 1997 were African American and 23 percent were Hispanic

- From 1996 to 1997, the number of African American clients increased by 5 percent

The program provided counseling and testing services to an additional 28,322 individuals in 1997, 20 percent more than in the previous year.

From 1996 to 1997, despite an increase of more than 2,000 enrolled clients, there were 170 fewer deaths. Out of the 32,612 enrolled clients, there were only 385 reported deaths.

Reduction of Perinatal Transmission

The Title IV program has been in the forefront at reducing perinatal transmission through a variety of activities. At many Title IV sites, perinatal transmission has been reduced to 5 percent or less. Recent research reveals that when pregnant women are treated at Title IV sites, seroconversion occurs much less often than when women are treated at other locations.

Clinical Trials

In 1997, 3,188 Title IV clients participated in clinical trials, an increase of 614 over the previous year. There was an increase in the number of clinical trial participants in every age category except young adults.

Administration

The Title IV program is located in the Comprehensive Family Services Branch of the HIV/AIDS Bureaus Division of Community Based Programs.

Adolescent Initiatives

In 1998, the Title IV program awarded five new Title IV Adolescent Initiative grants to identify HIV-positive adolescents and enroll them in care as a continuing program priority. As part of an active collaboration with the National Institutes of Health, the REACH (Reaching for Excellence in Adolescent Care and Health) Project has recruited more than 500 youth ages 12 to 18 in research studies of medical, behavioral, and psychosocial aspects of HIV/AIDS in adolescents at 15 clinical sites in Chicago, New Orleans, San Francisco, Boston, and Puerto Rico.

Part F

Special Projects of National Significance

The Special Projects of National Significance (SPNS) Program supports the development and evaluation of innovative HIV/AIDS service delivery models that have potential for replication, locally and nationally. As authorized in the CARE Act, $25 million was allocated to the SPNS Program from the FY 2000 appropriation. The SPNS increase knowledge about service delivery by evaluating models that hold promise for improving health outcomes. Since the program's inception in 1991, SPNS grantees have searched for solutions to problems in HIV care delivery and created innovative solutions. The majority of SPNS sites are community-based organizations, and public and private clinics.

Results are used to redirect resources into those service delivery methods yielding the greatest returns. Findings are disseminated to grantees and help improve outcomes for clients everywhere.

Each year, 3 percent of the total CARE Act appropriation, or $25 million, whichever is less, is invested in the SPNS Program.

Currently, there are 54 SPNS grants that vary in duration from 1 to 5 years, as well as approximately 30 additional care delivery activities. New projects are addressing palliative care, adherence, care for individuals leaving correctional institutions, care for substance abusers, and HIV care in managed care networks.

AIDS Education and Training Centers

The AIDS Education and Training Centers (AETC) Program supports education and training of health care providers who counsel, diagnose, treat, and manage care for individuals with HIV infection and to help prevent high risk behaviors that cause infection. The FY 2000 appropriation totaled $26.65 million.

The AIDS Education and Training Centers Program is a network of 15 regional centers (and 75 associated sites) that conduct targeted, multi-disciplinary education and training programs for health care providers. AETC have increased the number of health care providers who are educated and motivated to counsel, diagnose, treat, and manage care for individuals with HIV/AIDS, and have also helped prevent high risk behaviors that may lead to infection. AETC serve all 50 States, the Virgin Islands, and Puerto Rico

AETC focus on training primary health care providers (physicians, nurses, dentists) and, with a lesser emphasis, on mental health and allied health providers. AETC activities are based upon assessed local needs, with the majority of resources concentrated in areas of high HIV prevalence and incidence, and remaining resources allocated for suburban and rural needs. Each AETC involves at least one CARE Act Title I metropolitan area with high incidence of the disease.

HIV/AIDS Dental Reimbursement Program

The HIV/AIDS Dental Reimbursement Program assists accredited dental schools and post-doctoral dental education programs with uncompensated costs incurred in providing oral health treatment to patients with HIV disease. The FY 2000 appropriation was $8.0 million.

Eligibility

The HIV/AIDS Dental Reimbursement Program assists accredited dental schools and post-doctoral dental programs with uncompensated costs incurred in providing oral health treatment to patients with HIV infection. Eligible applicants must have documented uncompensated costs of oral health care for HIV-positive persons, and must be accredited by the Commission on Dental Accreditation. Funding takes into account the unreimbursed oral health costs incurred by each applicant dental school/program for patients with HIV infection compared to the total unreimbursed costs for patients with HIV infection incurred by all eligible applicants.

Testimony by

Sandra Thurman

Director, Office of National AIDS Policy

Before the

Senate Committee on Health, Education, Labor, and Pension

(HELP)

March 2, 2000

Chairman Jeffords, Senator Kennedy, and Members of the Committee. It is with mixed emotions that I appear before you today. More than ten years ago -- when we embarked on this journey together – we had all hoped that this hearing would not be necessary. We yearned to believe that a decade of slow but steady progress would produce a ~~cure~~ vaccine or a ~~vaccine~~ cure – or that ~~effective~~ prevention efforts would reduce the rate of new infections to nearly none. But the fact of the matter is – that while we have much to celebrate today – our Surgeon General has just reminded us that the AIDS ~~pandemic~~ epidemic is far from over. And in many ways – our job now grows more difficult, as HIV/AIDS moves most rapidly among traditionally hard to reach populations -- women, young people, people of color, and the poor.

HIV and AIDS has touched communities in each and every state across this country. And in big cities and rural towns – AIDS continues to devastate individuals, families, and communities, leaving them impoverished, suffering and in dire need of medical care and support. It is for this reason – and a host of others -- that I come to offer the strongest possible support from the President and the Administration for this Committee's bipartisan effort to reauthorize the Ryan White CARE Act.

Since its inception, the CARE Act has literally been a lifeline for hundreds of thousands of Americans in need. And over the years I have had the privilege to witness its programs at work from a variety of different vantagepoints.

As the executive director of AID Atlanta, the oldest and largest AIDS service organization in the South, I was honored to work with this Committee in 1989 on the development of this vitally important legislation. As a recipient of Title 1 and Title 2 CARE Act funds, I was proud to testify before this Committee in 1993 on the successes already taking hold as a result of your thoughtful action. And now, as director of the White House Office of National AIDS Policy, I am pleased to be able to come before you again as we chart our course forward – one which seeks to make this great effort even better.

The CARE Act has become a model for health care delivery not only in the United States, but around the world. It is a shining example of the good that can come from collaboration, coordination, and concerted action.

The CARE Act has brought together Republicans and Democrats, cities and states, hospitals and community-based organizations, providers and people living with AIDS – and the results are a tribute to the power of public-private partnerships. It has created a continuum of care that is both compassionate and cost-effective – one that saves both lives and money.

The CARE Act, taken as a whole, stitches together a tapestry of services that enables us to not only respond to locally driven needs – but to reflect the ever-changing face of AIDS.

- **Title 1** focuses on cities hardest hit by this pandemic – providing much needed relief to reduce pressure on already overburdened public health systems and to create community-based and locally controlled systems of care and support for thousands of individuals and families. When the CARE Act was

first passed there were 16 such hard hit cities. Today there are 51;

- **Title 2** acknowledges that AIDS knows no geographic boundaries. This title has enabled all states to develop consortia or systems of care, to provide private health insurance, and to expand access to essential drug therapies.
- **Title 3** helps to make primary care and early intervention services available to particularly disenfranchised populations in both rural and urban communities in cooperation with health centers, hospitals, and health departments;
- **Title 4** focuses much needed attention on the unique care and support needs of women, children, and families; and,

- **Title 5** allows for special projects of national significance, acting as a laboratory for demonstrating new and improved model efforts.

But this Act is so much more than the sum of its parts. As a whole, it serves individuals and families in the most efficient and effective way possible. This is not a one size fits all effort. The CARE Act gives each state and community the flexibility they need to weave together a means of caring for their own in a manner that is tailored to indigenous strengths and circumstances.

When the CARE Act was originally created we were sadly unable to do much for those who were sick – and many of the services provided were designed to help people die with dignity. Thankfully, much has changed.

The CARE Act is now solidly about living with HIV and AIDS. Since the last reauthorization, biomedical research has brought hope and renewed optimism with the discovery of protease inhibitors and combination therapies. But without the CARE Act, these cutting-edge therapies would have been about as ~~meaningful to many~~ access NO in Selma or the South Bronx as they ~~currently~~ are in South Africa. The CARE Act has made the promise of biomedical research a reality in the lives of people living with HIV and AIDS in every corner of this country.

Last year alone, approximately one hundred thousand people living with HIV and AIDS received access to drug therapy because of the CARE Act. This is particularly important given that half of the people served by the Act have family incomes of less than $10,000 a year – and the new drug "cocktails" cost more than $12,000 annually.

And we know all too well, that the drugs alone are not enough. Primary care and support services are vital to ensuring both access and adherence to these complex drug regimens. It is this comprehensive package of essential services that the CARE Act provides – and with impressive results.

The CARE Act has helped:

- to reduce both the frequency and length of expensive in-patient hospitalizations by at least 30%;
- to reduce AIDS mortality by 70%;
- to reduce mother-to-child transmission of HIV by 75%; and,
- to enhance both the length and quality of life for people living with AIDS.

According to a study done by the National Center for Health Statistics, between 1995 and 1997, the nation has seen a 30% decline in HIV related hospitalizations – resulting in nearly one million fewer HIV related hospital days. This represents a saving of more than $1 billion – money much more effectively invested in enabling people with HIV to live healthier and more productive lives. These positive outcomes highlight why the Ryan White CARE Act reauthorization is so imperative.

We stand at a critical juncture in this pandemic -- and we must be sure that the success of the CARE Act does not breed complacency but constructive action. Increasingly, the AIDS epidemic in the United States parallels the pandemic globally – with more and more disenfranchised people caught in the crossfire.

Last year, the CARE Act served an estimated half million people living with HIV and AIDS – and affected the lives of millions more. Nearly 6 in 10 of these people were poor. They were also five times more likely to be uninsured than those receiving care elsewhere, nearly 3 times more likely to be African American, and 50% more likely to be women. Clearly the CARE Act has followed the path paved by this epidemic – but challenges remain as HIV and AIDS moves deeper into underserved communities already plagued by poverty, homelessness, and substance abuse, and as treatment demands and costs continue to rise.

I am heartened to see that the Committee's bipartisan reauthorization effort currently being developed is designed to retool and upgrade existing CARE Act mechanisms to:

- expand access to essential services, particularly for vulnerable populations;
- improve the quality of care; and,
- increase the accountability of the overall program.

Surgeon General Satcher has talked at length about existing health disparities – and this Administration is firmly committed to moving on multiple fronts to eliminate these disparities. Certainly, the CARE Act has a vitally important role to play in that effort.

I applaud the Committee for moving forward with proposals which:

- increase program planning and responsiveness;
- create better CARE Act provider linkages with emergency rooms, drug treatment programs and other places that people in need may enter a system of care – and with Medicaid, CHIP, and other potential payers;
- develop capacity to deliver essential services in hard to reach rural and urban areas;
- create an incentive funds in the drug reimbursement program to help remove existing barriers to drug therapy; and,
- move toward a more performance based – outcome oriented system.

I believe that these program enhancements – built on the CARE Act's firm foundation will lead this vital effort -- and the millions whose lives depend on it -- safely into the future. We in the Administration look forward to working closely with all of you to secure the swift reauthorization of this landmark legislation.

In 1990, shortly after Ryan White's death, this Committee chose to build a legacy in his name. In so doing, the Committee Report read: "By dedicating this legislation to Ryan, the Committee affirms its commitment to provide, care, compassion, and understanding to people with AIDS everywhere. Ryan would have expected no less." Mr. Chairman and Members of the Committee – Ryan White changed our world – and so has your gift in his name.

As the Reverend Dr. Martin Luther King, Jr. once said: "Everybody can be great, because anybody can serve. You don't have to know about Plato and Aristotle to serve. You don't have to know Einstein's theory of relativity to serve. You don't need to know the second theory of thermodynamics to serve. You only need a heart full of grace and a soul generated by love."

Mr. Chairman, this Committee has demonstrated a heart full of grace in formulating, passing, and now sustaining the Ryan White CARE Act. It is act of service – to people living with HIV and AIDS, to all-enduring American family values, and to good government at its best.

Thank you very much.

3/2/00

Written Testimony Submitted by

Sandra Thurman

Director, Office of National AIDS Policy

To The

Senate Committee on Health, Education, Labor, and Pension (HELP)

March 2, 2000

(Please Note That Actual Testimony May Have Been Different Than Written Testimony)

Chairman Jeffords, Senator Kennedy, and Members of the Committee. It is with mixed emotions that I appear before you today. More than ten years ago – when we embarked on this journey together – we had all hoped that this hearing would not be necessary. We yearned to believe that a decade of slow but steady progress would produce a cure or a vaccine – or that effective prevention efforts would reduce the rate of new infections to nearly none. But the fact of the matter is – that while we have much to celebrate today – our Surgeon General has just reminded us that the AIDS pandemic is far from over. And in many ways – our job now grows more difficult, as HIV/AIDS moves most rapidly among traditionally hard to reach populations – women, young people, people of color, and the poor.

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Thank you very much.

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U.S. HOUSE OF REPRESENTATIVES

COMMITTEE ON BANKING AND FINANCIAL SERVICES

ONE HUNDRED SIXTH CONGRESS

2129 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515–6050

(202) 225–7502

February 18, 2000

Ms. Sandra L. Thurman
Director
White House Office of National AIDS Policy
736 Jackson Place
Washington, DC 20503

Changed to 3:30

Dear Director Thurman:

The Committee on Banking and Financial Services invites you to testify at hearing to be held on Wednesday, March 8, 2000, at 10:00 a.m., on the global AIDS crisis and on legislation (H.R. 3519) to create a new World Bank AIDS Prevention Trust Fund. The hearing will be held in Room 2128 of the Rayburn House Office Building.

The Committee would welcome your assessment of the impact of the global AIDS crisis on developing countries, especially in Sub-Saharan Africa, as well as the implications of the spread of AIDS for U.S. national interests. In particular, the Committee would be interested in your views on the unique role that the World Bank can play, in coordination with the United Nations and other relevant agencies, in combating the effects and spread of this devastating disease. In this context, the Committee would welcome ONAP's views and comments on H.R. 3519, the World Bank AIDS Prevention Trust Fund Act. A copy of the bill is enclosed.

Banking Committee rules require that written testimony be made available to Members of the Committee 24 hours in advance of a hearing. Accordingly, it would be appreciated if 200 copies of your testimony could be delivered to Room 2129 of the Rayburn House Office Building by 10:00 a.m. on Tuesday, March 7, 2000. In addition, the Committee would appreciate receiving a copy of the statement on a 3.5 inch computer disk which will be placed on the Committee's Internet home page in compliance with House Rule XI 2(e)(4).

If you have any questions regarding this invitation, please do not hesitate to contact Jamie McCormick at (202) 226-0473 or Cindy Fogleman (202) 226-3280. We look forward to your participation.

Sincerely,

James A. Leach
Chairman

Enclosures

cc: The Honorable John J. LaFalce

*** FINAL HEARING NOTICE***

TO: **All Members**
Committee on Banking and Financial Services

FROM: **James A. Leach, Chairman**

RE: **Full Committee Hearing**

The global AIDS crisis and pandemic in Africa; H.R. 3519, the World Bank AIDS Prevention Trust Fund Act

Wednesday, March 8, 2000
9:30 am
2128 Rayburn House Office Building

The Full Committee will convene a hearing on Wednesday, March 8, 2000, to address the impact of the HIV/AIDS crisis on the poorest nations of the world, particularly in hard hit Sub-Saharan Africa. Although the region has only 10 percent of the world's population, it has nearly 70 percent of the world's HIV cases and accounts for over 80 percent of global AIDS deaths. Experts report that the pandemic has orphaned some 10 million children and threatens to cut GDP in some countries by up to 20 percent by 2010. The hearing will examine international strategies to prevent HIV/AIDS and curb the toll in human suffering and lost economic productivity. Witnesses will also comment on H.R. 3519, the World Bank AIDS Prevention Trust Fund Act.

Witnesses scheduled to testify are listed below.

Panel I

- John F. Kerry, United States Senator
- Amo Houghton, United States Representative

Panel II

- Richard C. Holbrooke, the U.S. Ambassador to the United Nations
- Sandra L. Thurman, Director, White House Office of National AIDS policy
- Timothy F. Geithner, Undersecretary (International Affairs)
  U. S. Department of Treasury

Panel III

- Mary Fisher, Founder and Chair, Family AIDS Network
- Mpule Kwelagobe, Miss Universe 1999
- Mary M. Kanya, Ambassador, Kingdom of Swaziland

Panel IV

- James M. Sherry, M.D., Ph.D., Director of Program Development
  and Coordination, UNAIDS
- Gary Slutkin, MD, Professor of Epidemiology and International Health,
  University of Illinois School of Public Health, formerly Chief of Prevention, WHO Global Program on AIDS
- Catherine Wilfert, M.D., Scientific Director, Elizabeth Glaser
  Pediatric AIDS Foundation
- Thomas Welty, MD, Medical Epidemiologist, Cameroon Baptist
  Convention Health Board

Panel V

- Ronald Dellums, President Healthcare International Management Company,
  and Chairman, Constituency for Africa

U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON BANKING AND FINANCIAL SERVICES
ONE HUNDRED SIXTH CONGRESS
2129 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515–6050

(202) 225-7502

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736 Jackson Place
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Enclosures

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REPUBLICAN STAFF
COMMITTEE ON BANKING AND FINANCIAL SERVICES
GENERAL OVERSIGHT AND INVESTIGATIONS SUBCOMMITTEE

FACSIMILE TRANSMITTAL SHEET

TO: Sandy Thurman
FROM: Cindy Fogleman
OFFICE:
DATE: 3/2
FAX NUMBER: 456-2439
TOTAL NO. OF PAGES FOLLOWING COVER: 2
RE: FYI

☐ URGENT ☐ FOR REVIEW ☐ PLEASE COMMENT ☐ PLEASE REPLY

NOTES/COMMENTS:

We will shortly be releasing the expanded witness list - I think Dr. Gary Slutkin will be coming by the way —

H2-139 FORD HOUSE OFFICE BUILDING
WASHINGTON, DC 20515
(202) 226-3280

U.S. HOUSE OF REPRESENTATIVES

COMMITTEE ON BANKING AND FINANCIAL SERVICES

ONE HUNDRED SIXTH CONGRESS

2129 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515–6050

March 1, 2000

HEARING NOTICE

TO: **All Members**
Committee on Banking and Financial Services

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The global AIDS crisis and pandemic in Africa; H.R. 3519, the World Bank AIDS Prevention Trust Fund Act

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Witnesses scheduled to testify are listed below. Any additional witnesses will be announced later.

Richard C. Holbrooke, the U.S. Ambassador to the United Nations
Timothy F. Geithner, Undersecretary (International Affairs), U. S. Department of Treasury

Sandra L. Thurman, Director, White House Office of National AIDS policy
Mary Fisher, Founder and Chair, Family AIDS Network
Ronald Dellums, President Healthcare International Management Company, and
Chairman, Constituency of Africa.

THE WHITE HOUSE

WASHINGTON

February 24, 2000

Mr. Robin Williams
c/o Mr. David Steinberg
via fax

Dear Robin:

I understand that Senators Kennedy and Jeffords have invited you to testify before the United States Senate HELP Committee on the Ryan White Comprehensive AIDS Resources and Emergency (CARE) Act. As you may know, the federal government currently contributes nearly $2 billion to the "Ryan White bill" – which provides essential health care and support services to hundreds of thousands of individuals and families living with HIV/AIDS. In big cities and small communities, this program has literally given life and hope to those most in need. Unfortunately, it is scheduled to expire this fall unless extended ("reauthorized") by Congress prior to their adjournment.

The President and I are strongly committed to continuing this lifeline, as is a bipartisan coalition on Capitol Hill. Senators Kennedy and Jeffords have been longtime champions for AIDS, and for the Ryan White bill, and they will be leading the charge in the Congress. We hope to kickoff this effort with a highly visible and informative Senate hearing. This is a chance for those who have been touched by the bill to tell their stories and to convince the Congress that real lives hang in the balance. Your work has given voice to the millions who often suffer in silence. Your leadership and advocacy on behalf of the poor, the homeless, and people living with HIV and AIDS has helped to open both minds and hearts. The President and I commend you for that.

Your presence in Washington on March 2nd would send a powerful message that few others have the capacity to deliver. In so doing, you would shine a spotlight on a vitally important program – and help to save countless lives. It would mean a great deal to the President, to me, and to the millions of Americans affected by AIDS if you could join with us at this critical juncture.

If you or your staff have any questions, please do not hesitate to call Michael Iskowitz at (202)253-9035. Please know that we stand ready to do whatever we can to make this trip as quick and painless as possible. Also, we would be happy to supply briefing materials and a draft statement for your review – if this would be helpful.

Thank you very much for your time and consideration.

Sincerely,

Sandra L. Thurman
Director
Office of National AIDS Policy

United States Senate

COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS

WASHINGTON, DC 20510-6300

February 9, 2000

Ms. Sandy Thurman
Director
White House Office of National AIDS Policy
736 Jackson Place, N.W.
Washington, D.C. 20503

Dear Ms. Thurman:

Thank you for agreeing to testify before the Senate Committee on Health, Education, Labor, and Pensions on the topic of the re-authorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The hearing will be held on March 2, 2000, beginning at 9:30 a.m. in the HELP Committee room, 430 Dirksen Senate Office Building, Washington, D.C. The Dirksen Building is located at the corner of First Street and Constitution Avenue, N.E.

As you well know, the Ryan White CARE Act provides vital resources to address the health care needs of thousands of individuals living with HIV and AIDS. I am very much interested in your thoughts on the future of this epidemic and in learning of the other recommendations you may have to further enhance services available for people with HIV and AIDS.

I am most interested in having an exchange of views and ideas among witnesses. Therefore, I would appreciate it if you would limit your comments to no more than five minutes. Any written testimony you submit will be included as part of the printed hearing record. After all the witnesses have presented their statements, Members of the Committee will ask questions and engage in dialogue with the witnesses.

In order to facilitate preparation for the hearing and related press inquiries, I request that you provide the list of items I have enclosed. Should you have any questions, need any additional information, or require any special provisions (overhead, slide projector, screen, etc.), please contact Sean Donohue at (202) 224-6770. Your testimony is an important contribution to this hearing; I look forward to seeing you on March 2nd.

Sincerely,

James M. Jeffords

SPD:mdc
cc: The Honorable Edward M. Kennedy
Enclosure

Items to Submit for Hearing
Before the
Senate Committee on Health, Education, Labor, and Pensions
By Close of Business, Friday, February 25, 2000

1) A copy of your biography, FAXed to William Fleming. The FAX number is (202) 228-0411. The biography will assist Senator Jeffords in introducing you at the hearing, so please feel free to make note of accomplishments you would like him to highlight.

2) Fifty copies of your written statement, sent or delivered to the address below. You may wish to include additional copies of your statement for distribution to members of the press on the day of the hearing. Any additional copies should be sent to the name and address provided below.

3) A diskette copy of your testimony, clearly labeled with your name and formatted in WordPerfect 6.1 should accompany the copies of the written testimony. Alternatively, you may transmit your testimony via electronic mail (in WordPerfect 6.1 for Windows or lower; ASCII; or DOS text) to William_Fleming@labor.senate.gov

William Fleming
Committee on Health, Education, Labor, and Pensions
United States Senate
725 Hart Senate Office Building
Washington, D.C. 20510

* * *

THE WHITE HOUSE

WASHINGTON

February 9, 2000

Mr. Tom Hanks
c/o Ms. Heidi Schaeffer
PMK
955 South Carrillo Drive, Suite 200
Los Angeles, CA 90048

Dear Mr. Hanks:

I understand that you have been invited to testify before the United States Senate HELP Committee on the Ryan White Comprehensive AIDS Resources and Emergency (CARE) Act. As you may know, the federal government currently contributes nearly $2 billion to the "Ryan White bill" – which provides essential health care and support services to hundreds of thousands of individuals and families living with HIV/AIDS. In big cities and small rural communities, this program has literally given life and hope to those most in need. Unfortunately, it is scheduled to expire this fall unless extended ("reauthorized") by Congress prior to their adjournment this.

The President and I are strongly committed to continuing this lifeline, as is a bipartisan coalition on Capitol Hill. Senators Kennedy and Jeffords have been longtime champions for AIDS, and for the Ryan White bill, and they will be leading the charge in the Congress. We hope to kickoff this effort with a highly visible and informative Senate hearing. This is a chance for those who have been touched by the bill to tell their stories and to convince the Congress that real lives hang in the balance. It is clear from your performance in the movie "Philadelphia", and from your comments since, that you understand the challenges of people living with AIDS and that you are committed to helping others understand these realities. The President and I commend you for that.

Your presence in Washington on March 2nd would send a powerful message that few others have the capacity to deliver. In so doing, you would shine a spotlight on a vitally important program – and help to save countless lives. It would mean a great deal to the President, to me, and to the millions of Americans affected by AIDS if you could join with us at this critical juncture.

If you or your staff have any questions, please do not hesitate to call Michael Iskowitz at (202) 456-2437 or (202) 253-9035.

Thank you very much for your time and consideration.

Sincerely,

Sandra L. Thurman
Director
Office of National AIDS Policy

REPUBLICAN STAFF
COMMITTEE ON BANKING AND FINANCIAL SERVICES
GENERAL OVERSIGHT AND INVESTIGATIONS SUBCOMMITTEE

FACSIMILE TRANSMITTAL SHEET

TO: Sandy Thurman	FROM: Cindy Fogleman
OFFICE:	DATE: 3/7
FAX NUMBER: 456-2439	TOTAL NO. OF PAGES FOLLOWING COVER: 2
RE: FYI	

☐ URGENT ☐ FOR REVIEW ☐ PLEASE COMMENT ☐ PLEASE REPLY

NOTES/COMMENTS:

2128 Rayburn

TKassotlow@CFR.ORS

Senator Reed → Mark Smith 224-6976

Senator Graham

H2-139 FORD HOUSE OFFICE BUILDING
WASHINGTON, DC 20515
(202) 226-3280
FAX: (202) 225-2478

U.S. HOUSE OF REPRESENTATIVES

COMMITTEE ON BANKING AND FINANCIAL SERVICES

ONE HUNDRED SIXTH CONGRESS

2129 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515–6050

March 7, 2000

*** FINAL HEARING NOTICE***

TO: **All Members**
Committee on Banking and Financial Services

FROM: **James A. Leach, Chairman**

RE: **Full Committee Hearing**

The global AIDS crisis and pandemic in Africa; H.R. 3519, the World Bank AIDS Prevention Trust Fund Act

Wednesday, March 8, 2000
9:30 am
2128 Rayburn House Office Building

The Full Committee will convene a hearing on Wednesday, March 8, 2000, to address the impact of the HIV/AIDS crisis on the poorest nations of the world, particularly in hard hit Sub-Saharan Africa. Although the region has only 10 percent of the world's population, it has nearly 70 percent of the world's HIV cases and accounts for over 80 percent of global AIDS deaths. Experts report that the pandemic has orphaned some 10 million children and threatens to cut GDP in some countries by up to 20 percent by 2010. The hearing will examine international strategies to prevent HIV/AIDS and curb the toll in human suffering and lost economic productivity. Witnesses will also comment on H.R. 3519, the World Bank AIDS Prevention Trust Fund Act.

Witnesses scheduled to testify are listed below.

Panel I

- John F. Kerry, United States Senator
- Amo Houghton, United States Representative

Panel II

- Richard C. Holbrooke, the U.S. Ambassador to the United Nations
- Sandra L. Thurman, Director, White House Office of National AIDS policy
- Timothy F. Geithner, Undersecretary (International Affairs)
  U. S. Department of Treasury

Panel III

- Mary Fisher, Founder and Chair, Family AIDS Network
- Mpule Kwelagobe, Miss Universe 1999
- Mary M. Kanya, Ambassador, Kingdom of Swaziland

Panel IV

- James M. Sherry, M.D., Ph.D., Director of Program Development and Coordination, UNAIDS
- Gary Slutkin, MD, Professor of Epidemiology and International Health, University of Illinois School of Public Health, formerly Chief of Prevention, WHO Global Program on AIDS
- Catherine Wilfert, M.D., Scientific Director, Elizabeth Glaser Pediatric AIDS Foundation
- Thomas Welty, MD, Medical Epidemiologist, Cameroon Baptist Convention Health Board

Panel V

- Ronald Dellums, President Healthcare International Management Company, and Chairman, Constituency for Africa

Committee on Government Reform

Subcommittee on Criminal Justice, Drug Policy and Human Resources

B-373 Rayburn House Office Building
Washington, DC 20515
voice: (202) 225-2577
facsimile: (202) 225-1154

DATE: July 27

TO: **Name:** Sandra Thurman

Organization: The White House

Phone: _____

Fax: 456-2439

FROM: Mason Alinger

Total No. of Pages
(Including cover sheet): _____

COMMENTS: Hard copy to follow

If there are any problems in the transmission of this facsimile, please call the sender at (202) 225-2577.

Congress of the United States

House of Representatives

COMMITTEE ON GOVERNMENT REFORM
2157 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515–6143

MAJORITY (202) 225–5074
MINORITY (202) 225–5051
TTY (202) 225–6852

July 28, 1999

Ms. Sandra Thurman
Director, Office of National AIDS Policy
The White House
736 Jackson Place, NW
Washington, DC 20503

Dear Ms. Thurman:

On behalf of myself and the members of the Subcommittee on Criminal Justice, Drug Policy and Human Resources, I would like to thank you for taking the time to testify before the subcommittee on the issue of the global HIV/AIDS epidemic. Your testimony assisted our consideration of the challenges faced by the Federal government in determining its role in combating the epidemic.

As mentioned at the close of the hearing, I have also included a set of follow-up questions that I did not get a chance to present to you at the hearing. Please provide the subcommittee with answers to the questions for the record no later than **Friday, August 20, 1999**. The responses and any additional supporting documentation can either be faxed to 202-225-1154, sent electronically to mason.alinger@mail.house.gov, or mailed to:

Subcommittee on Criminal Justice, Drug Policy and Human Resources
B-373 Rayburn House Office Building
Washington, DC 20515

Please feel free to share your ideas and information with my staff and me as we continue to work together on this important topic.

Sincerely,

John L. Mica
Chairman
Subcommittee on Criminal Justice, Drug Policy, and Human Resources

QUESTIONS FOR SANDRA THURMAN

1. According to the Washington Post (July 20; page A4), the recent White House announcement of $100 million for prevention and treatment of HIV/AIDS will come from existing funds, including $48 million for a program that provides "education, counseling and blood screening." Can you tell us specifically where this money is coming from, and how it will be used? How much will go directly for drug treatment for people who are HIV positive and how would they be selected?

2. Congressman Berry testified that he "...welcomes the Administration's proposal to increase the U.S. investment in fighting HIV/AIDS in Africa by $100 million...but noticeably it will not help one more patient get life-saving medicines that are now available." What would you recommend to address the needs of over twenty million infected persons who are in need of treatment? Would you support the government's making available to the World Heath Organization the drugs that the US has the patent rights to? Don't you think that relying upon periodic announcements of recommended aid could raise false hopes, and that more comprehensive approaches are required to save significant lives, such as has occurred in the U.S. with effective drug treatment? What else would you recommend to help these countries get affordable treatment?

3. Since you've seen the situation in South Africa first-hand, would you describe it as an emergency? If so, wouldn't you rather see the United States government respond to this crisis as if it *were* an emergency, rather than threatening trade retaliation against a country like South Africa for enacting a law that appears to be in accordance with existing international laws and agreements, and has not even been implemented as yet?

4. Is your office on record as opposing parallel imports or compulsory licensing of AIDS treatment drugs by nations that are experiencing major AIDS epidemics? What is your policy regarding the expansion of HIV/AIDS drug availability in developing nations?

5. Do you support this Administration's "assiduous, concerted campaign to persuade the Government of South Africa" (state department report) to give up on their Medicines Act?

6. Do you think that drug treatments should be withheld from the millions now suffering due to fears that new strains of HIV/AIDS might develop? If so, should this policy apply to the U.S.? Why or why not?

FRIST
ENNESSEE

COMMITTEES:
Commerce, Science, and Transportation
Budget
Health, Education, Labor, and Pensions
Foreign Relations

United States Senate

WASHINGTON, DC 20510

February 15, 2000

Ms. Sandra L. Thruman
Director
Office of National AIDS Policy
The White House
Washington, D.C.

Dear Ms. Thruman:

On February 24, at 2:30 PM, in 419 Dirksen Senate Office Building, I will chair a hearing of the United States Senate Committee on Foreign Relations Subcommittee on African Affairs regarding AIDS in Africa. On behalf of the Committee, I respectfully request that you present your expert testimony.

The Committee is especially interested in the Administration's overall strategy to address the HIV/AIDS crisis in Africa. Specifically, we would like your assessment of the effects on the economic viability of the continent; the best prospects for combating the disease in the global economic environment; the consequent priorities and decisions on spending, and whether current U.S. and multilateral efforts maximize potential; and the issues surrounding retro viral drugs and the prospects for a vaccine.

Your position as the President's advisor will be an especially valuable element for the Congress as we begin to consider new and additional strategies to address what will certainly be the greatest policy and humanitarian challenge for the United States on the continent. The United States can be a powerful force for positive change in Africa, and the nature of our response can be the difference between life and death for millions. I look forward to working with you on this critical issue, and I am grateful for the assistance you will give us in our progress toward our shared goals.

With warm regards, I am

Sincerely,

Bill Frist, M.D.
United States Senator

United States Senate

COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS
WASHINGTON, DC 20510-6300

February 9, 2000

Ms. Sandy Thurman
Director
White House Office of National AIDS Policy
736 Jackson Place, N.W.
Washington, D.C. 20503

Dear Ms. Thurman:

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cc: The Honorable Edward M. Kennedy
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United States Senate
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Washington, D.C. 20510

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