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"Nurses: The Unsung Heroes in the Battle Against AIDS
Statement by Sandra Thurman
Director,
White House Office of National AIDS Policy

Tambussen
the Servers

Thank you Jim for that nice introduction, and thank you all so much for inviting me to speak with you today. For a host of personal and professional reasons -- it is indeed a treat for me to be the guest of the Emory School of Nursing. As you may know, Atlanta is my home and the Emory School of Nursing has played an important role in the career development of a several very special family members.

My Aunt Joy Bradley, who I yanked out of retirement to help start the AIDS Clinic at AID Atlanta, received both her bachelors and masters degrees in nursing from Emory. And my mother, seeking to follow in the footsteps of her older sister, also entered nursing school here at Emory. Unfortunately, when she flunked out, she was forced to settle for becoming a lawyer instead. And in her eyes, that was a tremendous step down.

B Focus formal comments on nursing - ~~add~~ and then answer any questions or address any particular ~~CDF~~ issues you might find of interest

as mother Teresa

But not everyone is cut out to be a nurse. In fact, it seems to me that being a nurse takes a very special combination of compassion, commitment, and skill. Throughout history, especially during difficult times, it has always been nurses who have cared for the sick and educated a frightened public. It has always been nurses who have reached out not only to individuals, but to families and entire communities in need. And it is that very combination of unique skill and talents that has called nurses to the front lines of our nation's battle against HIV and AIDS.

We are at a critical juncture in the fight against this deadly virus. With hope on the horizon, many Americans and too many policy makers yearn to believe that the worst is behind us. Yet the sobering truth is that the AIDS epidemic far from over.

With no vaccine or cure in sight, we are actually far closer to the end of the beginning than we are to the beginning of the end. In big cities, small towns, and rural communities across this country -- the epidemic rages on. And increasingly, it is women, young people, families, and communities of color that are caught in the crossfire.

But AIDS is not somebody else's problem -- we are all living with AIDS. America is a family and our family has AIDS. Our children, our parents, our brothers and sisters, our extended families, and our communities are all at risk. And ignorance, apathy, denial, and exhaustion continue to take a serious toll. Luckily, for people living with AIDS and for all Americans, nurses are well positioned and well trained to help respond to our collective cry for help.

Don't get me wrong -- we have made and continue to make great strides. But we cannot allow progress to breed complacency. Present and future generations are in jeopardy...and there is more, much more that needs to be done. And in a host of different ways and from a variety of different vantage points, nurses can and must help to provide some of this essential leadership.

-- <u>The first and most obvious area of need for leadership is that you as nurses can continue to organize and provide a kind of care for individuals living with HIV and AIDS that goes far beyond a strict medical model</u>. Since the time of Florence Nightingale, the founder of modern nursing, you have understood that good health is about much more than managing disease --

it is about integrating the physical, psychological, and spiritual aspects of wellness. Nurses have always recognized the importance of human dignity and of family participation -- and these issues are at the core of modern HIV care and treatment.

Nurses provide essential care across the full continuum of HIV disease beginning with early intervention -- maximizing the time that people stay well and participate fully in all aspects of life.

Acknowledging this important need, we developed an early intervention clinic when I was at AID Atlanta. The clinic was created and managed by nurses, with primary care provided by nurse practitioners. The clinic has been a great success, and today, Dr. Jim Pace, a faculty member here at the Emory School of Nursing, continues to be a vital part of the early intervention team at AID Atlanta. This is only one small example of nurses making a difference. From Savannah to Seattle -- it is happening all over this country.

Nurses are also the direct care givers during and between acute episodes of illness. Symptom management and life planning are at the core of nursing -- and as we seek to move toward treating HIV and AIDS as a chronic illness -- this becomes

increasingly critical.

Nurses understand the need to provide emotional support as individuals and families learn to live with HIV disease. You have created and perfected the "art" of caring for individuals without judgment, helping them to integrate treatment into their everyday lives. This requires not only knowledge, but insight, compassion, and the ability to see not a just disease but a whole person. It requires a willingness to tailor interventions to individuals and families in a way that recognizes the real needs of each person in a family system.

And certainly nurses play an equally important role in the end of life and in hospice care. In fact, some of the most brilliant and profound moments I have been privileged to witness have been among nurses and patients and their loved ones at the end of their lives. At that all important time, a focus on quality of life and on family ties and transitions -- has been most intuitively understood by nurses.

[transition on care challenges]

-- A second important area of need for leadership is that you as nurses can continue your special focus on community education and prevention. Nurses have a longstanding tradition of responding to the needs of individuals, families, and communities -- especially among the poor and the disenfranchised. This has been true in both rural and urban areas.

Nearly a century ago, Lillian Wald and Mary Brewster established the Henry Street Settlement House on the lower east side of New York as a shining example of nurses reaching out to the urban poor. Equally as important was Mary Breckinridge's work in rural Appalachia in establishing the Frontier Nursing Service. More recently, nurses have played a vital role in responding to the needs of childhood immunizations, Polio, TB, and HIV.

The need for education about HIV and AIDS continues to be enormous. Many Americans still lack the information they need to save their lives and protect their futures. Still others are now confused by recent news reports about a "cure" or a "cocktail" that somehow makes the virus disappear. And sadly, fear and homophobia and racism still hold us back -- and prevent us from

effectively facing the challenges of this epidemic.

Nurses are trusted members of communities and can help us develop approaches to HIV/AIDS education that work -- both for special target audiences and for the public at large. Targeted education must culturally sensitive and relevant -- speaking to people in language they will understand, accept, and act on. Education of the broader community must also communicate essential information -- but do so in a manner that builds bridges not walls.

These are difficult challenges and require the assistance and support of individuals who have the capacity to communicate across barriers that divide us. Traditionally, nurses have been able to effectively deal with difficult issues -- such as sexuality -- in a manner that is real without causing riots in the streets. HIV/AIDS prevention will only work if it is a community response. And nurses, as credible health educators, can help mobilize communities to take realistic action on HIV/AIDS education.

Nurses also have a role in helping persons with HIV understand their treatment options and support adherence to drug therapy. Some people seem to be

developing a belief that HIV/AIDS is a manageable disease and is less serious than in years past. Nurses can educate the public and patients about the realities.The drug "cocktail" that we have heard so much about is hardly a new version of the martini.It is a complicated regimen of up to 30 pills per day that have to be taken in precisely the right way or they can do more harm than good.

We certainly have no shortage of news on the AIDS front in recent months. But while we have good news about declining rates of death....we have no decline in the overall rate of new infections. While we have declines in the rates of infection in gay white men, we have dramatic increases in the rate of infection in women, people of color and adolescents...with a disproportionate impact on the poor....particularly poor women and women of color...most of whom have children or are of childbearing age. Often these families are caught in cycles of despair, poverty, violence and drugs. These are not Americans who receive their health care from a private physician in a private hospital. Helping these families requires outreach, trust building, cultural sensitivity, and comprehensive support....all of which has traditionally been provided, in large part, by nurses working in clinics and public health programs across this nation.

-- **And finally, a third important area of need for leadership is that you as nurses can continue to bring your special skills to advocacy and the development of public policy.**

The ~~bottom~~ foundation ~~line~~ of advocacy is education – but the educating of decision makers becomes particularly challenging when the subject matter is sensitive – who better than nurses are equipped to breach those sensitive subjects in a way that informs – but does not threaten –

Certainly the ANA, the National Association of nurses in AIDS care, and a variety of other organizations have a long and successful track record on the National Scale – as does the Georgia Nurses Association on the State level –

~~This~~ Our ability to provide good quality care to patients ~~requires that~~ depends ~~on our~~ on the policys we help create, ~~to a~~ on ~~ability~~ ~~to~~ the policys ~~result~~ And ~~consequently~~, as the needs of patients change – as they ~~inevitably~~ have and ~~will~~ inevitably quest for new treatments goes on – well as our ~~fight to treat~~ – ~~as we medicate~~ ~~HIV wages on~~ – our policys must change. This virus is not static – ~~our policies~~ our advocacy ~~actions~~ must not be ~~at~~ either –

In Closing –

glue –
Change – system, ~~[illegible]~~ treatment, epidemic
nurses rise to challenge

thank you –