

**REMARKS OF MICHAEL CALLEN
TO THE NEW YORK
CONGRESSIONAL DELEGATION**

I am a gay man with AIDS and I have been asked to speak to you this morning to personalize the tragedy of AIDS. I will attempt to do this, but since what brings us together is the fact that you are politicians, I will also try to explain how the political context surrounding AIDS inevitably becomes part of the experience of each AIDS patient.

Each person's experience with AIDS is different. I can only tell you my story.

I was diagnosed with AIDS in December, 1981, although I believe I was immune depressed for over a year before.

I have been hospitalized twice since then and continue to have my health monitored by my physician and by a number of privately funded research projects.

Although I believe I will beat this disease, I am continually confronted by media reports telling me that no one has recovered from this syndrome, and that my chances of living past 1984 are poor. Figures provided by the Centers for Disease Control indicate that 80 percent of those diagnosed when I was are now dead.

My life has become totally controlled by AIDS and my fight to recover. I begin each day by checking my body for Kaposi's sarcoma lesions and other signs of serious health complications. I am subject to fevers and night sweats and an almost unendurable fatigue. I live with the fear that every cold or sore throat or skin rash may be a sign of something more serious.

At age 28, I wake up every morning to face the very real possibility of my own death. I am a member of a support group for AIDS patients which meets once a week in the cramped offices of the National Gay Task Force. In addition, in August of 1982, I formed a support group of gay men who have been diagnosed with AIDS. Because we have no community service center or other space in which to meet, the support group I formed meets in my living room.

Whatever I am asked by members of the media or by curious healthy people what we talk about in our groups, I am struck by the intractable gulf that exists between the sick and the well. What we talk about is survival.

We talk about how we're going to buy food and pay rent when our savings run out.

We talk about how we are going to earn enough money to live when some of us are too sick to work.

We talk about how it feels to get fired from our jobs because of unjustified fears of raging and lethal contagion--fears based on ignorance and unfounded speculation--fears which are being fanned by the Centers for Disease Control's endorsement of the view that we may be carrying and spreading a lethal, cancer-causing virus--fears that AIDS may be spread by casual, non-sexual contact which are being spread by men like Dr. Anthony Fauci of the National Institutes of Health.

We talk about the pain we feel when our lovers leave us out of fear of AIDS.

We talk about the friends who have stopped calling.

We talk about what it feels like when our families refuse to visit us in the hospital because they are afraid of catching that "gay cancer."

We talk about what it feels like to be kept away from our nieces and nephews and the children of our friends because our own brothers and sisters and friends are afraid we'll infect their children with some mysterious, new, killer virus.

We compare doctors and treatments and hospitals.

We share our sense of isolation: how it feels to watch doctors and nurses come and go wearing gowns, gloves and masks.

We share our anger that there are doctors and health care workers who refuse to treat AIDS patients.

We share our tremendous sense of frustration and desperation at being denied treatments such as plasmapheresis because many hospitals fear that our blood may "contaminate" the machines.

We share our fears about quarantine--the rumors that separate wards are being created to isolate us from other patients--rumors that certain hospital workers' unions have threatened to strike if forced to treat AIDS patients or wash their laundry--rumors that closed hospitals are being readied for the quarantine of AIDS patients and maybe even healthy members of at-risk groups.

We talk about our fears that the personal data we have volunteered to the CDC to help solve the mystery of AIDS may be used against us in the future. We are asked if we have had sex with animals. We are asked to detail sexual practices which are illegal in a number of states. We are asked to admit to the use of illegal drugs. The answers to these questions are stored in government computers. We are asked for trust that the confidentiality of this information is being safeguarded--only to find out that the CDC has already made available its list of AIDS patients to The New York Blood Center. We wonder who else has seen this information.

Mostly we talk about what it feels like to be treated like lepers who are treated as if we are morally, if not literally, contagious.

We try to share what hope there is and to help each other live our lives one day at a time.

What we talk about is survival.

AIDS patients suffer in two basic ways. We suffer from a life-threatening illness, and we suffer the stigma attached to being diagnosed with AIDS.

The end to both aspects of this suffering depends on finding the cause(s) and cure(s) for AIDS. And that can only happen if research money is released in amounts proportional to the seriousness of this health emergency. In order to confront and challenge the ignorance and insensitivity which we, as AIDS patients, must face on a daily basis, we need answers to the pressing questions of cause, cure and contagion.

The political context in which AIDS is occurring cannot be ignored. AIDS is affecting groups which remain disenfranchised segments of American society: homosexual men, heroin abusers, Haitian entrants and hemophiliacs. This so-called 4-H club has been joined by prisoners (most of whom are either Hispanic, IV drug abusers or both); female prostitutes; and the children of high risk groups who are also victims of poverty.

Despite the fact that in the four years since AIDS was first recognized, AIDS has killed more people than swine flu, toxic shock syndrome, Legionnaires disease and the Tylenol incident combined, the response of the federal government to AIDS--the worst epidemic since polio--has been to ignore it and hope it just goes away. If such a deadly disease were affecting more privileged members of American society, there can be no doubt that the government's response would have been immediate.

As a gay man, I could never decide whether I should be pleased with how far the gay rights movement has come since 1969 or whether I should be disgusted and angered at how far we have to go.

The government's non-response to the AIDS crisis has answered this question for me.

I was raised as a small-town boy from Ohio: white, male and middle class. As a gay man, the pain I suffered from prejudice was largely emotional—not for the most part economic. So my political response was modified by patience. On the whole, I believed in democracy. I believed in America.

I felt it would only be a matter of time before education and the destigmatization of gayness would bring me my rights.

But now I am fighting for my life. I am facing a life and death crisis that only the resources of the federal government can end, and I am shocked to find how naive I've been.

Not only is my government unwilling to grant my right to love whom I choose—my right to be free from job discrimination—my right to the housing and public accommodation of my choosing. This same government—my government—does not appear to care whether I live or die.

Prejudice and oppression are words often bandied about too freely. But the tragedy of AIDS has made many gay men take a new look at the situation of America's other disenfranchised groups. We are beginning to see that homophobia and racism are not, as some of us thought, totally unrelated. We are beginning to see that America's fear and ignorance of homosexuals and its hate and bigotry toward black and brown people are not just co-incidental. We are beginning to see that a Haitian infant dying in poverty in the South Bronx and the death of a white, middle class gay man in Manhattan are sadly, but undeniably, interconnected.

These are the politics of AIDS. When the history of this country's response to this health crisis is written, it will stand as yet another appalling example of America's apathy, indifference and inaction.

History teaches that such prejudice and bigotry ultimately poison the whole society—not just those at whom it is directed. If the personal suffering of human beings is not enough to motivate you to fight for increased AIDS funding, let me offer you another way to justify to your constituents the release of federal research funds.

Newsweek recently called AIDS "the medical mystery of the century." Solving this mystery will surely benefit all Americans—indeed all humankind. Finding the cause of AIDS may well hold the key to cancer—maybe to all disease.

Do not allow the shortsightedness of prejudice to delay us any longer from discovering how the immune system defends us from disease.

Whatever you and your colleagues do or don't do, whatever sums are or are not allocated, whatever the future holds in store for me and the hundreds of other men, women and children whose lives will be irrevocably changed—perhaps tragically ended—by this epidemic, the fact that the Congress of the United States did so little for so long will remain a sad and telling commentary on this country and this time.

I do not envy you your role in this matter any more than you must envy mine. 1983 is a very bad year to be an elected official, just as it is a very bad year to be a gay man, a Haitian entrant or a child living in poverty. And surely when you first dreamed of holding public office you did not, in the furthest reaches of your imagination, foresee that your duties would include having breakfast on a Monday morning with a homosexual facing a life-threatening illness. You can be sure that ten years — five years — or even one

year ago, I could not have imagined the possibility that I, too, would be up here begging my elected representatives to help me save my life. But there you are. Here I am. And that is exactly what I am doing.

Thank you.