

ACQUIRED IMMUNE DEFICIENCY SYNDROME





NEWSLETTER

NEW YORK, N.Y. NUMBER TWO JANUARY 1983

Where Are We Now?

Our second *Newsletter* comes to you at a time when the AIDS problem would seem to have reached a very dark day. Medical scientists cannot really tell us much more now than they could six months ago, when our first *Newsletter* came out. The signals we get from responsible medical authorities are confusing, in part because these authorities are confounded by AIDS and very few doctors like to say, "I don't know." Case numbers are doubling every six months. There is an almost 40% mortality rate. There are currently three new cases a day nationally and one-and-ahalf new cases a day in New York, which still is the city where 50% of all cases occur. Gay men still represent 74% of all victims. There is the woeful prediction that there will be ten thousand cases in two years' time.

It's very hard for us not to cry out in anger, frustration, fear, desperation, and utter bewilder-

ment: "How many people must die before something happens!"

By "something" we mean a concerted all-out effort by our community and by our country to make everyone recognize that we are in the midst of the worst epidemic to hit us since polio and to mobilize ourselves into the great and effective agency for action and change which this country is capable of becoming in time of emergency.

For it is hard to imagine a worse emergency, or an enemy to match the stealth and horror of this

insidious epidemic, an unknown disease that hides itself.

This being so, it seems to us at Gay Men's Health Crisis that there are still too many people who

don't know what's going on, or, worse, acting as if they don't know what's going on.

1. The funding for an all-out research assault has been very slow in coming. Our epidemic is already a year-and-a-half old. Although an earlier award provided \$2 million to the CDC for AIDS, there is at this moment no money for specific AIDS research pending in either house of Congress.

The National Institutes of Health, which has an annual budget of four billion dollars, has said they will release—"sometime this year"—at least \$3 million through their National Cancer Institute and at least \$2 million through their National Institute of Allergy and Infectious Disease. But they have already received \$55 million worth of grant requests from hospitals, doctors, scientists, and institutions who have been clamoring to do research into AIDS.

Five million dollars doesn't buy much research these days, or represent much of a commitment on the part of our country when you consider the number of victims we have sustained, which, as

of January 13, totaled 333 AIDS deaths.

And when we read articles like the following from the New York *Times* of October 10, 1982, we are angry about the priorities of our country: "The United States Ambassador, . . ., donated \$25 million Friday on behalf of the Reagan Administration to aid relatives of 57 [natives of a small foreign country] killed in a flood and landslide at a mining camp . . . along with a message from President Reagan saying, 'The American people join me in sending sympathy to those injured, their families and the families of those who lost their lives.' "

2. The straight media have been extremely negligent. Remember the almost daily sympathetic attention they lavished on Legionnaire's disease, toxic-shock syndrome, the Tylenol scare, swine flu-victims from all of which total far fewer than we have sustained from AIDS? Now that AIDS is appearing in more heterosexuals, and in babies, the media have recently paid more attention, but,

strangely, only a little more.

Constant national media attention helps exert pressure in Washington to release the flow of funds. And without this media attention we have been deprived, for most of the past year-and-a-half, of our nation's main network of communication: how word is spread, information disseminated, 'alerts sounded. (Six men recognized they had KS lesions from viewing the slides that were shown at GMHC's Second Open Forum two months ago.)

Although the New York Native has been excellent in keeping its readership constantly apprised

of what is happening, the total circulation of all gay publications is unfortunately tiny compared to our total numbers.

So how can we tell each other, all of us, that what's happening now is literally a matter of life or death?

3. There has been a great lack of communication between the gay community and the medical/scientific community. Studies are constantly announced and undertaken by people who have only the vaguest notions of how we live. A mere request in the *Native* for volunteers, with a promise of a complete physical examination or some free "test for AIDS," will net more than enough volunteers in a matter of hours. From these men, statistics are garnered by heterosexuals unsophisticated in our ways that are then publicized in medical journals and the media as fact. But the men who respond to these requests are most often those at higher risk and do not necessarily represent a cross section of the gay community.

4. We want to mention the complex issue of doctors who have felt unable to help guide us through this terrible period. Medical research, and health policy must be shaped on local and national levels. It is this policy that will help determine how this epidemic—and our lives—will be handled as local and federal governments will have no choice but to become involved. The areas of gay.health and sexual medicine are still very loosely defined. If we don't field our own experts, representing us, fighting for us, there is no telling what will happen to us as more and more pressure is brought to bear on officials to "find an answer" and who then might take the path of least

resistance and scapegoat gay men.

Thus far, not enough doctors have stepped forward, identified themselves as gay, and pitched

in to help on a public level.

5. Here in New York, the meetings GMHC instituted with City Hall, which are reported on elsewhere in this *Newsletter*, have been very slow in achieving results. In no way have we gained the significant acknowledgment of crisis that San Francisco has, with that city's emergency bequest of \$300,000 to its AIDS-related endeavors. Indeed, our top-priority request—that our city help us find space which AIDS patients could use for their own lounge and support group sessions, to be with their own—remains unfulfilled. For lack of permanent space, AIDS and KS support groups have been forced to move around from week to week, often to top-floor walkups that KS patients lack the strength to climb.

Working with our city government is a very slow process. We are not discouraged, yet, but we are a long way from receiving the recognition gay communities have achieved in such cities as San

Francisco, Los Angeles, Houston, and Washington.

6. The gay community itself is not yet united on AIDS. There is one thing we must not allow AIDS to become, and that is a *political* issue among ourselves. It's not. It's a health issue for us. And it's a national public health emergency issue. This may be the hardest task of all for many of us. We've been too accustomed to fear, particularly the fear our sexual freedom, so hard fought for, will be taken away from us. But we must realize that sex is not the fabric holding our community together; that's a very questionable assumption about our commonality indeed. We must realize that we are much, much more, that we have a sense of self and identity and relating as exists in any religion or philosophy or ethnic background, and in which sex plays no more a role than it does in heterosexual identity. And if it takes an emergency epidemic to teach us this lesson, then let this be one of life's ironies.

We all want this epidemic stopped immediately. GMHC is hardly pleased to report that no miracle drug or cure has shown itself. And all of us want to know how to live our lives now. All doctors everywhere dealing with AIDS are under immense stress, and the most stressed of all are the physicians of New York who treat large gay populations—a position of truly heart-breaking frustration. These doctors are telling us to lessen the number of sexual partners we come in contact with, so that, if a transmissible agent is the culprit, we will lessen our chances of getting or

giving it. No doctor we know of is trying to make moral judgments with this advice. Quite the contrary. They cannot bear to see one more AIDS diagnosis, and so they are understandably in favor of seeing us live at the expense, perhaps, of our temporarily suspended sexual liberty. But GMHC believes that each individual must make his own decision.

Since, as of January 13, there were 891 cases of AIDS in 33 states, 67 cases in 13 foreign countries, and 426 cases in New York City, it is hard for us, for the moment, to refute this advice.

though everyone is entitled to make his own decision.

All of us, however, must do everything in our power to make our community and our government and our contry recognize the frightening implications of these rising numbers. We must orchestrate this concern, locally, nationally, in Washington, and pray that this country understands that what is happening to us, and is now happening to heterosexuals, demands immediate attention. How many of us are carrying within us the seeds of this mysterious disease? It is hard to live in New York now without the torment of this question. And how many of us must die before an effective national plan of attack is begun?

Listen to these words from Dr. James Curran of the CDC: "How are we going to spend the next ten years? That's how long it could take before a causal agent can be found, along with its cure.

We don't have enough people worried about this yet."

Gay Men's Health Crisis is now one year old. We're certainly no longer the bunch of kids who got together and brought you a disco dance. From six men we have grown to over 300 men, each of whom is giving a portion of his weekly time to combating AIDS, and we are now a major social service organization without - yet - any funding from any state, city, or federal sources, only from

you, our community.

We have raised over \$150,000; given away almost \$50,000 to research; printed and distributed some 25,000 copies of our first Newsletter (which was so well-received that it is used as a training manual in many hospitals and was even requested by the Library of Congress) and at least 100,000 of this one; prepared and distributed 300,000 Health Recommendation Brochures (in English, Spanish, Creole, and French) with a list of symptoms; fielded almost five thousand Hotline emergency calls, which included hundreds of referrals to doctors; created a Patient Service program that includes Crisis Intervention Counselors (who stay with a patient from immediately after diagnosis as having AIDS), individual and group support therapy, a network of buddies to visit and do chores for those ill, legal advisors, and financial aid guidance through the complexities of the welfare system; arranged Open Forums for the community to hear and question doctors prominent in AIDS care; arranged contact with representatives of our Mayor and Congressmen; helped institute measures to protect the community from unsuitably prepared research studies; investigated and registered complaints against improper medical treatment and hospital care; set up training seminars for doctors, psychiatrists, psychologists, social workers, health care professionals, and concerned laymen in all areas of AIDS concerns, including how to deal with your friend or lover who may be terminally ill; served as a central source for the media so that most of that which has appeared has been accurate and sensitive-and all of these services have been provided by volunteers and provided free.

That GMHC has accomplished all of this (and mostly in the last six months) and that so many responsible gay men have stepped forward to accomplish all of this is one of the most inspirational developments to ever occur in the New York gay community. We have never encountered so much love between men as we have felt in GMHC and watching this organization grow in response to our community's terrible new needs has been one of the most moving experiences we have ever been privileged to share.

We would not be here in such strength without you. You have been responsible as well. That you have continued to send in your checks and volunteer your services or stop a GMHC member in the street and say Thank You - this has been inspirational too. There are few communities that, when asked, and within the space of one short month, would loan, interest-free, an organization

\$130,000, from 130 men, so that we could effectively plan the greatest gay fund-raising event of all time. And, with \$60,000 worth of tickets already sold to our Circus before we've even really started our sales campaign, it looks like you're going to support our Circus as well.

It goes without saying that we desperately need your support to continue. We need your contributions and we need your names for our mailing list and we need you to come to our Circus on April 30. Like every other living, human being, we need you to keep telling us you approve of us

and what we're trying to do.

We must not let this awful sense of unknowing that AIDS yet represents divide us. We might all - each and every one of us - be potential AIDS victims. More than ever before we must fight together now-to help those who are already ill with AIDS, and to help insure our own future on this earth

The Board of Gay Men's Health Crisis, Inc.