AIDS research

Big enough spending?

Washington

THE federal response to acquired immune deficiency syndrome (AIDS), the mysterious and uniformly fatal disease whose victims are almost exclusively homosexuals and intravenous drug users, has been a predictable target for charges of government discrimination. Would the government be doing more, critics ask, if the victims were Scandinavians or tennis players?

Despite the recent provision of \$12 million in emergency funds for the federal epidemiology and research effort, that question will not go away, and last week a House of Representatives subcommittee heard city health officials, homosexual rights activists, AIDS researchers and AIDS victims say that the government could be doing more, could be doing it faster and could be more candid in admitting that it needs more money to back up its declaration of AIDS as the "number one" public health priority.

The criticism of the federal role comes at a time when the number of new AIDS cases continues to accelerate. The Centers for Disease Control (CDC) reported late last week that an average of 53 new cases were reported each week in July, twice the rate recorded in January and nearly five times the rate recorded a year ago. New cases reported in the past six weeks account for 17 per cent of the 1,972 reported since 1981.

Nearly 90 per cent of the patients continue to be members of two high risk groups, male homosexuals and intravenous drug users; the remainder are haemophiliacs and others who have received blood transfusions, recent Haitian immigrants to the United States (although

there are increasing suggestions that many, if not all, are members of one of the high risk groups), and a few who do not appear to have any of the identified risk factors.

AIDS researchers seem generally to agree that research support from the federal government has now reached adequate levels. But the lingering question remains why it took so long for that support to become available and why, until a few months ago, federal health officials continued to insist that existing funds were adequate and that everything that could be done was being done.

Dr Marcus Conant, co-director of the Kaposi Sarcoma Clinic at the University of California, San Francisco, accused the Public Health Service (the federal agency that includes CDC, the National Institutes of Health and other health agencies) of playing a numbers game to conceal the inadequacy of support for AIDS research and monitoring. Earlier this year, Assistant Secretary for Health Edward Brandt, in announcing that AIDS was number one priority, asserted that \$14.5 million would be spent this year on the problem.

But Conant said this figure reflected a "double accounting" that included projects on immune function and cancer that were under way before AIDS was even identified and funds for which were appropriated as long as four years ago. Brandt, while not specifically denying the point, adds that if all basic research were included that could lead to treatment for AIDS, the figure would be \$166 million.

But both inside and outside the government there is considerable confusion over just how much new money has been made

available for new work specifically on AIDS.

Brandt stands by the assertion that enough money is being spent, and suggests that those who are "throwing numbers around" on how much is needed should back up their claims with specific advice on how the money should be spent. But under questioning by subcommittee chairman Ted Weiss (Democrat, New York), it became clear that Brandt's position on the adequacy of support has been a constant refrain, even during the time that Brandt himself was seeking to divert \$12 million from other areas to AIDS.

In April this year, Brandt and other Public Health Service (PHS) officials were telling a House appropriations subcommittee that no new funds were needed; just a month later, they were asking the same committee for permission to reprogramme the \$12 million. A memorandum from the director of CDC to Brandt itemized \$2.25 million in immediate needs, including \$1.5 million to restore funds previously diverted from other areas. Congress decided to go one better by appropriating the \$12 million as an immediate supplemental budget for fiscal years 1983 and 1984. "Federal officials who say that enough money is being spent on AIDS are simply mouthing some required political line", Conant said.

Another target has been what critics see as foot-dragging by the National Institutes of Health (NIH) in issuing research grants on AIDS. The first announcement of new grants specifically for AIDS research was published in August 1982, a year after the first cases were reported, and grants were awarded in April and May this year. Proposals in response to a second announcement were due this month and will be awarded shortly.

PHS officials say that the usual time for developing a request for proposals, reviewing applications and awarding grants is 18 months; the first AIDS awards were made 14 months after the go-ahead in January 1982 from NIH's scientific advisory council. So far, 14 grants have been made, or about 30 per cent of the approved applications — roughly the going rate for NIH as a whole

The inertia of the NIH bureaucracy seems more to blame than any special indifference to AIDS, and Brandt has offered assurances that future research funding will be expedited. But the sudden influx of the new funds may add another bureaucratic tie-up: some AIDS researchers say there is now an undirected scramble by the various NIH institutions to get into the act, each supporting research and calling meetings on a particular aspect of AIDS that falls within their purview. Stanley Matek of the American Public Health Association urged Brandt to call a conference of experts within and without the government to establish a master research plan and avoid "shooting in the dark with scientific scatter guns".

Stephen Budiansky

Confidential matters

"PEOPLE aren't going to answer questions about illegal acts truthfully to a federal official", is how one AIDS patient sums up a problem unique to this disease which threatens to undermine vital epidemiology research. "There is a need to reassure communities who have no reason to trust the government."

Homosexual rights groups say that before AIDS patients can be expected to reveal details of their sexual case histories and admit to illegal acts such as prostitution or drug use, the Centers for Disease Control (CDC) will have to do more than say "trust us". Incidents such as CDC's delivery of a list of names of AIDS patients to the New York Blood Center — perhaps by accident — have hardly allayed fears.

In response to this concern, and aware of the damage that underreporting or omission of important details from case histories could do to epidemiologic investigations, CDC has proposed a system whereby case reports from state and local health departments would be identified only by number. Several local health departments, including New York City, have already adopted such a policy and are refusing to provide names to CDC.

CDC's efforts to reassure AIDS patients that their files will be kept secret may have bordered on the hypocritical, however, when it refused to supply information to a House of Representatives subcommittee investigating the federal response to AIDS (see main story). Representative Ted Weiss accused the Department of Health and Human Services of "stonewalling, from Secretary [of HHS Margaret] Heckler on down" when it denied subcommittee investigators access to CDC files. Calling the CDC's newfound concern for patient confidentiality "the height of cynicism". Weiss said that "we are not only uninterested in seeing names ourselves, we question whether CDC should have that information" in the first place. Last week, CDC was still refusing access to congressional investigators.

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