

THE POLITICS OF AIDS



By J.S. Taub

As an illness, AIDS is terrible to behold, striking mostly young adults just before their most productive years, ravaging them physically and causing them to be shunned by the rest of society. For the medical community, AIDS is difficult to treat; there is no cure and enormous resources are required to provide comfort to the afflicted.

For the political community, too, AIDS has proven to be a difficult challenge. It's a disease whose primary modes of transmission — homosexual sex and illegal drug use — carry negative overtones for most of the population. Furthermore, it's an illness whose control may depend on finding a new balance between two of society's most cherished values: the need to protect itself versus the desire to preserve individual liberty. That political context is proving to be a fertile field for politicians who believe there may be advantages to jumping in on one side or the other of the AIDS debate. Particularly loud are those on the extremes, whose vociferous debate threatens to silence more moderate voices.

Further complicating the political scene has been a vacuum of leadership within the Deukmejian administration on the issue of AIDS, leaving the field open to the state's legislators who are expected to consider a wide variety of AIDS-related legislation this year. Those who treat AIDS patients are fearful that the political issues will distract government officials from those things they can do to really have an effect on the spread of AIDS.

Issues surrounding the widespread mandatory blood testing for evidence of Human Immunodeficiency Virus (HIV), the cause of AIDS, threatens to divert energy, attention,

and resources away from prevention, education and treatment programs for people with AIDS, critics say.

Controversy over blood testing of certain population "groups" — decisions of whom to test, who gets the results, what is done with the results, what happens to those who test positive and where the line gets drawn — moves AIDS out of the public-health spectrum and into the political spotlight.

Politicization of AIDS creates an uncertain climate for those with the disease and for "seropositive individuals" — those who have tested positive for the AIDS virus but are still healthy. It raises the blood pressure of California's public-health experts, who denounce mandatory testing as useless — a "quick fix," designed to exploit peoples' fear of AIDS.

That AIDS is political is reality. How AIDS issues get resolved determines whether or not California will continue to lead the nation in AIDS research, prevention and treatment.

Lawmakers and public-health officials are looking to the Deukmejian administration for guidance in their response to the AIDS epidemic, and they complain they are getting no feedback.

Critics allege the governor is emitting mixed signals about his commitment to confidentiality and anti-discrimination. They say despite the governor's apparent monetary largesse, Deukmejian's reactive AIDS policy has created a void, allowing legislatively-driven political agendas to dominate the proceedings.

Dr. Carl L. Smith, health officer of the Alameda County Health Agency, says, "We are looking for leadership. The state has viewed itself as a fiscal intermediary to manage grants and contracts, but it hasn't developed a comprehensive AIDS response plan. We need new ideas and new approaches." Smith says lack of a comprehensive strategy for



preventing HIV transmission has made California "subject to inappropriate legislative action;" specifically, proposals for widespread mandatory blood testing.

The administration's track record on AIDS is double-edged. No doubt, with \$70.2 million proposed for research, treatment, surveillance and education for fiscal 1988-89, California allocates more money to fight AIDS than any other state.

Among California's accomplishments are: a computerized AIDS registry; an AIDS Advisory Committee chaired by a gay Republican; universal blood-donor screening; establishment of the hugely successful alternative test-site program for voluntary, anonymous HIV testing; an AIDS vaccine research and development program complete with clinical trials; and a slate of pilot projects for hospice, home health and attendant care for people with AIDS.

The Department of Health Services (DHS) has also sought a Medicaid waiver allowing Medi-Cal to reimburse patients for these services. It is expected to be in place this Summer. Medi-Cal outlays alone will hit \$40 million in fiscal 1988-89.

Yet, closer readings of Deukmejian's concern over AIDS reveal a governor ambivalent about AIDS, who declines to take a pro-active role on a difficult policy issue. He has, as much as possible, avoided the moral debate over AIDS. His unwillingness to stake out a position has created a mixed message for those on either side of the debate and has occasionally undermined the efforts of his own health advisors. When pushed, Deukmejian has generally sided with conservatives, refusing to grant anti-discrimination protections to those afflicted with the disease.

Missing from the governor's approach, observers say, is

a clear statement of his philosophy. While Dr. Kenneth Kizer, executive director at the DHS, has expressed personal opposition to mandatory blood testing and emphasizes the importance of confidentiality and anti-discrimination, he refuses to speak directly for the administration on these issues. This sends a confusing signal to policymakers.

"It's real quiet up there," says Democratic state Senator Gary Hart of Santa Barbara, who chairs the Senate Select Committee on AIDS. He suggests that Deukmejian is caught between his conservative base of support and his own public-health experts. "This is a profile in uncourage. The governor doesn't want to alienate the right wing constituency that believe discussions of sex are immoral. AIDS is a disease that doesn't affect his constituency, so why go to bat if there's a political price to pay," Hart points out.

But whom AIDS affects or ignores may be just a matter of time. California has the second largest AIDS caseload in the country, accounting for 25 percent of all reported cases nationwide. As of June 1987, the Department of Health Services reported 8669 cases of AIDS and 4682 deaths from the disease. Los Angeles and San Francisco account for 80 percent of the state's caseload. Because of 20 percent under reporting, Kizer estimates 10,000 cases of AIDS have already occurred here.

This will get worse. By 1991 AIDS will be the state's seventh leading cause of death. Some 50,000 Californians will have caught the disease and 34,000 will have died. Pediatric cases will mount to more than 300. Currently, up to half a million are now infected with the virus and still healthy. Health officials are uncertain how many of these will actually develop the disease, with estimates varying between 30 and 100 percent, with incubation periods of up to 10 years.

Continued on next page

The economics of AIDS is still a question mark. The legislative analyst predicts that, by 1991, annual medical care costs associated with AIDS could soar to \$406 million, with cumulative costs hitting \$1.7 billion. Moreover, as patients lose jobs and insurance, a heavier burden will be placed on Medi-Cal and the state's safety net hospitals. Already, the proportion of AIDS patients covered by Medi-Cal has shot up from 12 percent to 20 percent, and is climbing. Medi-Cal could spend as much as \$415 million in cumulative costs by 1991. These figures don't match lost productivity, as AIDS strikes the baby boom generation at the height of its socioeconomic contribution to society. By 1991 premature death could set the state back by \$9 billion.

AIDS is the worst infectious epidemic of the 20th Century, a pandemic stretching around the globe. But in California, AIDS is owned by gay men who account for 90 percent of all cases. Now, only 2 percent of all cases involve IV drug users; 2 percent are from blood transfusions; 1 percent are hemophiliacs; and 1 percent are heterosexuals. Though the incidence of AIDS among minorities is still low, there are ominous signals that a new rush of cases will explode in the Black and Hispanic communities, which now account for 9 percent and 10 percent of cases, respectively.

This contrasts with the experience on the East Coast where, needle sharing, heterosexual relations and perinatal transmission account for nearly half of AIDS cases. However, a state-sponsored study here says Black IV drug users are nine times more likely to be infected than other IV drug users. For the foreseeable future, the demographics of AIDS are expected to hold steady.

AIDS is caused by HIV, a retrovirus, which is contagious under specific circumstances of homosexual or heterosexual intercourse, sharing contaminated needles, through contaminated blood products or transfusions, and from a pregnant woman to her baby. A 2.5 percent "don't know" classification comes from death-certificate data, where information on risk behavior cannot not be established.

Because there is no casual transmission, AIDS is not a plague. It is a blood-borne disease transmitted by consensual behaviors. Health officials say that in absence of a cure or vaccine, the public must be educated and motivated to change risky consensual behaviors to halt transmission.

HIV directly attacks the immune system, leaving the body vulnerable to a host of opportunistic infections and cancers. The federal Center for Disease Control (CDC) has specified conditions under which an illness must be classified as AIDS. However, a spectrum of HIV-related diseases that strike seropositive individuals collectively — called AIDS Related Complex (ARC) — raises the number of sick people at least three-fold. People with ARC sometimes go on to develop AIDS. There is no reliable count of ARC patients in California.

Against this backdrop, California lawmakers are gauging the pulse of their constituents. The mood is mixed. Public opinion has certainly "hardened" over the AIDS issue in the sense that people are more aware of AIDS and how it is transmitted. And they want the government to do more.

"We are witnessing powerful conflicting trends of compassion, denial and blame," says Benjamin Schatz, an attorney with the National Gay Rights Advocates in San Francisco. "The more people learn about AIDS, the more they want to see something done. This naive desire for immediate action is vulnerable to exploitation. Testing sounds firm and concrete. Education sounds weak and amorphous," Schatz explains.

Liberals and moderates in both houses of the Legislature will spend this session fending off attacks from right-

wing hardliners calling for widespread mandatory blood testing. "Hit pieces," targeting those who seem "soft" on AIDS, are reportedly in the works. "There is a lot of fear about being on the wrong side of a hit piece. Legislators are bound by the restraints of their districts and are often afraid to say anything," according to one legislative consultant who asked not to be named.

Senator Bill Lockyer, a Hayward Democrat, admits his anxiety over the effect a right-wing hit piece could have in his conservative, suburban district. "We frequently worry about how many constituents would be grumpy enough not to vote for you after seeing one of those things," he says.

Though battle lines appear drawn, everyone seems ready to cut a deal. Much depends on the fate of AB 87, a bill introduced last year by then-Assemblyman, now San Francisco Mayor Art Agnos. A liberal, Agnos is closely allied with San Francisco's gay community. AB 87 is a sweeping philosophical-political statement. It declares AIDS a physical handicap for non-discrimination purposes; refines disclosure laws; and requires informed consent before taking an antibody test. It incorporates parts of Surgeon General C. Everett Koop's report on AIDS into the California code and creates a California Commission on AIDS to advise the governor and the Legislature. The bill has cleared the Senate and is back in the Assembly for consideration of amendments. The governor has not declared himself on the bill.

Much also depends on the fate of several controversial bills introduced by state Senator John Doolittle, a Citrus Heights Republican, who is seeking widespread mandatory blood testing. Using a two-tiered, building-block strategy of legislation and ballot initiative, mandatory-testing and reporting advocates launched the first offensive of their campaign at state prisoners, prostitutes, the mentally ill, pregnant women and marriage-license applicants.

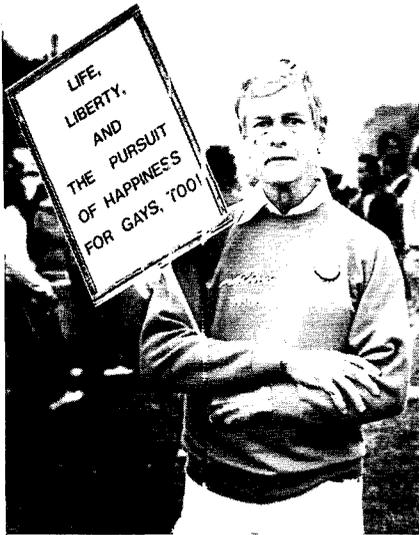
Legislation seeking disclosure of antibody positive tests to public-health officials; penalty enhancements for knowingly donating infected blood or committing sex crimes or prostitution once a person has tested positive; and testing of the mentally ill passed the Senate only to stall in the Assembly Health Committee.

Other measures were amended beyond recognition. A bill which would have required mandatory blood testing for all marriage applicants was softened to make the test voluntary. "We turned the marriage-license notification bill inside out. That's what we intend to do with the other testing bills," says Michael Housh, an Agnos aide.

Another Doolittle bill, SB 1432, allows life and disability insurers to test for HIV antibody status as a condition for coverage. Current law prohibits testing or using test results for that purpose.

The right wing supports mandatory testing and reporting of all antibody positives to public-health authorities to identify HIV "carriers." This, they say, is necessary to protect the health of the uninfected, because they insist medical authorities have not established all modes of HIV transmission. They oppose anti-discrimination protections, viewing them as a smoke screen for gay rights. They scorn targeted education and behavior modification programs emphasizing safe sex and safe fix as advocating promiscuity and drug use.

"We are dealing with a politically protected disease," states Fullerton's Republican Congressman William Dannemeyer. "I stand for the heterosexual ethic and I will not apologize." Denying that people with AIDS have been stigmatized, Dannemeyer believes that employers should discriminate against "someone who espouses a homosexual lifestyle." Dannemeyer places needle users in a class by



Bradley Roberts of San Francisco in Washington for the October 1987 Gay Rights March.

themselves. "It is debasement of the body and anyone who chooses to engage in this conduct should live with the consequences." The radical right wing thinks AIDS should be treated like every other communicable disease. Reporting is necessary, they say, for statistics, contact tracing and to warn those unaware of their HIV status.

Meredith Miller, 33, says she's not a junkie or a hooker and doesn't know anything about the homosexual lifestyle. But she can tell people something about discrimination against

those with AIDS. On Miller's quiet block in San Francisco's Haight district, she fears harassment if her neighbors find out she has AIDS. She arranged for friends to adopt her two children, six and nine, so they won't face discrimination in school or on the streets.

Once, Miller recalls, for the half-week her physician was on vacation, hospital personnel refused to care for her. "They wouldn't clean my room, they left the food tray outside my door, they wouldn't come into the room unless they wore gowns and booties and goggles. All I saw were eyeballs. I was traumatized," Miller says.

Kizer at the DHS also calls Dannemeyer's approach inappropriate. Kizer's view is shared by Surgeon General Koop, the U.S. Public Health Service, the Institute of Medicine of the National Academy of Sciences, the American Medical Association and the California Medical Association. "These calls are usually based on the erroneous notion that AIDS is somehow like measles, tuberculosis or other such diseases," Kizer says.

Smith, in Alameda County, is concerned that, "If reporting names is to be the kingpin of an AIDS plan, it will divert money from important activities like education, counseling and case management. When you make venereal diseases reportable, they don't get reported. Then, there will be no adequate measure of the level of infection in the community."

The medical community doesn't dispute the value of HIV antibody testing when it is confidential or anonymous, and used for counseling and behavior modification. That is the principle behind the state's alternative test-site program. However, public-health experts warn that identifying and reporting individuals will cause those with the highest risk to flee the system for fear of persecution, isolation or quarantine. While underground, they will continue to spread the disease because they haven't been counseled on how to stop transmission.

Health experts say mandatory testing creates a sense of false security because some infected people will not test positive the first time. Then too, the percentage of false positive results also rises to unacceptable levels in low-risk populations. Health officers criticize the right wing approach because it de-emphasizes the amount of follow-up testing necessary. Testing assumes no risky behavior has taken place between tests, which is unenforceable.

Dannemeyer doesn't buy the argument. "When people get sick they are going to seek medical treatment," he says. Yet public-health experts warn that asymptomatic infected individuals afraid to seek testing can remain healthy for five years or longer, while infecting their sex and/or needle partners and children.

Doolittle doesn't see why anyone would object to a reportable HIV test. "People would cooperate. Only some selfish individual would place his job over the safety of other people."

Meredith Miller says those with the disease would sooner die or go to guerrilla clinics than seek medical treatment under those conditions.

Doolittle, who supported Proposition 64, the 1986 Lyndon LaRouche ballot initiative, also believes that people in professions like food handling and early education, should undergo mandatory testing. As stipulated in Proposition 64, which was soundly defeated by voters, if such persons test antibody positive, they should be removed from their jobs.

What would they do? "Let's be serious. They have to get another job. These are low-level, entry-level jobs anyway. They don't need retraining. And if they do, they'll have to pay for it out of their own pockets or go on public assistance and Medi-Cal," Doolittle states.

Doolittle also says all teenagers should be tested for HIV because, "They are the next biggest risk group. Education without testing puts the cart before the horse." Doolittle says these proposals are just ideas, for now. "We haven't thought it all through, yet," he says.

What has been thought through, and has proved a stunning success, is the state's alternative test-site program. Alternative test sites offer free blood testing and counseling. Since 1985, 150,000 individuals have participated in the program to find out their antibody status, learn how to use condoms for safe sex and how to sterilize IV needles with bleach for safe fix.

Noting the success of persuasion, critics call Doolittle's proposals shallow, "high concept" and politically opportunistic. This sector of conservatives, critics say, are exploiting public distaste for homosexuality and drug abuse to parlay a gay-bashing social policy agenda.

Doolittle denies that he is a homophobe, but admits, "If it were only the offbeat populations — homosexuals and IV drug users — that get AIDS, no one would care about it. I am concerned because we know it is spreading through the heterosexual population."

Meredith Miller is one heterosexual, non-drug user, with AIDS who feels threatened and demeaned by Doolittle's brand of concern. "They want to create another little holocaust. I'm sick. I don't want to be locked up. I haven't hurt anyone."

Says one legislative consultant who agreed to speak anonymously, "The message of the right wing is that this is an unknown source of infection and that somehow the government can root out all the infected people and leave the rest in a disease-free society. They are saying that people cannot be responsible for themselves."

John Doolittle expresses deep contempt for the medical community's emphasis on prevention. "The CDC is distorting the facts with warm reassurance and false impressions that are intentionally paternalistic and unfair. The fact is that we may know how the virus is spread, but we don't know how it isn't spread." Doolittle distrusts public-health experts who insist that AIDS cannot be transmitted through casual contact, air or mosquitoes. He charges, instead, that the state's

public-health policy is being fashioned by "ardent homosexual-rights activists who have been the driving, organizing force for policy on AIDS."

"I am not interested in homosexual rights," protests Dr. Donald Francis of the CDC. "If they would actually listen to the message, they would see I'm concerned with transmission. How could I possibly be promoting homosexuality when it has a 50 percent chance of killing you?" Francis thinks it's ironic that AIDS prevention programs have generated so much heat. "I'm frankly amazed we don't have more of a constituency on the right, since the prevention programs stress less sex."

Doolittle acknowledges that his colleagues in the Legislature are unlikely to let his bills stand. "I know that our position will have to be changed," Doolittle states. "It's not my preference, but I'm willing to deal in reality to get what I want."

Should he not get what he wants in the Legislature, Doolittle will fall back on the California Physicians for Logical AIDS Response Public Health Act of 1988, which is collecting signatures for the November ballot. This proposal bans alternative test sites, abolishes confidentiality and establishes mandatory contact tracing. It fines doctors who refuse to report HIV positives to public-health authorities and forces them to testify against patients accused of sex crimes. The initiative is sponsored by Paul Gann, a close ally of Doolittle and Dannemeyer, who also has AIDS. The initiative concedes the quarantine issue to the backers of Lyndon LaRouche, whose "Son of 64" ballot initiative will go before the voters in June.

Lawmakers will not have a protracted period to scale the learning curve on AIDS. Their responses to controversial issues will depend not only upon a rational understanding of the facts, but an instinctive sense of what is, and is not, legiti-

mate in a free society.

One plot on the decency index will be whether or not to test all state prisoners for exposure to HIV. Presently, prisoners with AIDS and some antibody positives, are isolated in a special facility in Vacaville (see story, page 60). This marks the beginning of a two-tiered prison system. Opponents to testing inmates realize that trying to sell criminals, prostitutes and the mentally ill to their constituents will be a tough PR call. But they warn that "writing off" such unattractive populations is shortsighted because it gives hard-liners a foundation upon which to enact measures that could eventually affect the mainstream.

But even some moderates feel uncomfortable with current testing laws. And there are some signs they are working their will on current legislation. Laws have been passed that permit spouses to be notified when AIDS is diagnosed and a change permitting the "relaxation of some of the super-confidentiality rules for some hospital patients" has been inacted at the behest of Assemblyman William Filante, a Republican from San Rafael and a physician. Senator Lockyer also complains that some rules are inflexible. "The confidentiality laws were written without an adequate look at the exceptions. They have to be thought out better," he says.

But Congressman Henry Waxman, a liberal Democrat from Los Angeles, believes mandatory testing will ultimately prove a bogus issue. "Because the epidemic has affected gay men and drug abusers, the political right cried out against homosexuals. They would like to use it in the 1988 elections, but they will not be successful. Their position is clearly irresponsible and they will be unsuccessful in using it as a partisan issue. People aren't going to be swayed by a political football regarding public health."

Perhaps the motif for lawmakers this session should be "safe legislation." 

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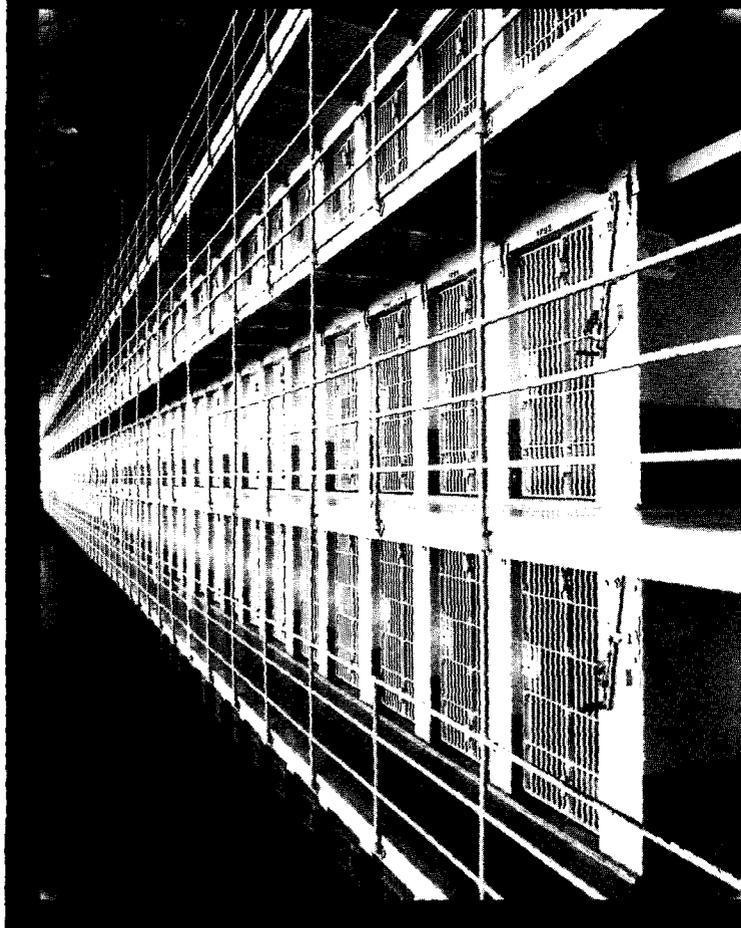
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AIDS IN PRISON

A prison within a prison for

By Marc Lifsher

Locked behind steel doors, warehoused in two isolated wings of a high-security prison, 112 men kill time, hoping to finish sentences before dying from AIDS.

The inmates, all diagnosed as suffering from some form of acquired immune deficiency syndrome, are restricted to "L" and "N" Wings — narrow hallways lined with tiny, two-man cells. They live at the California Medical Facility, a 4600-man prison at Vacaville between San Francisco and Sacramento, where the State Department of Corrections is coping with its small piece of a modern-day epidemic.

The epidemic, a baffling disease which destroys the human body's defense system, has added a new dimension to imprisonment for the men on "L" and "N" Wings and for a handful of other AIDS victims ill enough to be transferred to hospitals.

The spectre of AIDS, which has already killed at least 5700 Californians (including 31 convicted criminals), is particularly frightening to the state's 66,000 prisoners. Many of them are intravenous drug users or engage in homosexual sex and know they could be

Marc Lifsher is a Capitol correspondent for The Register of Orange County.

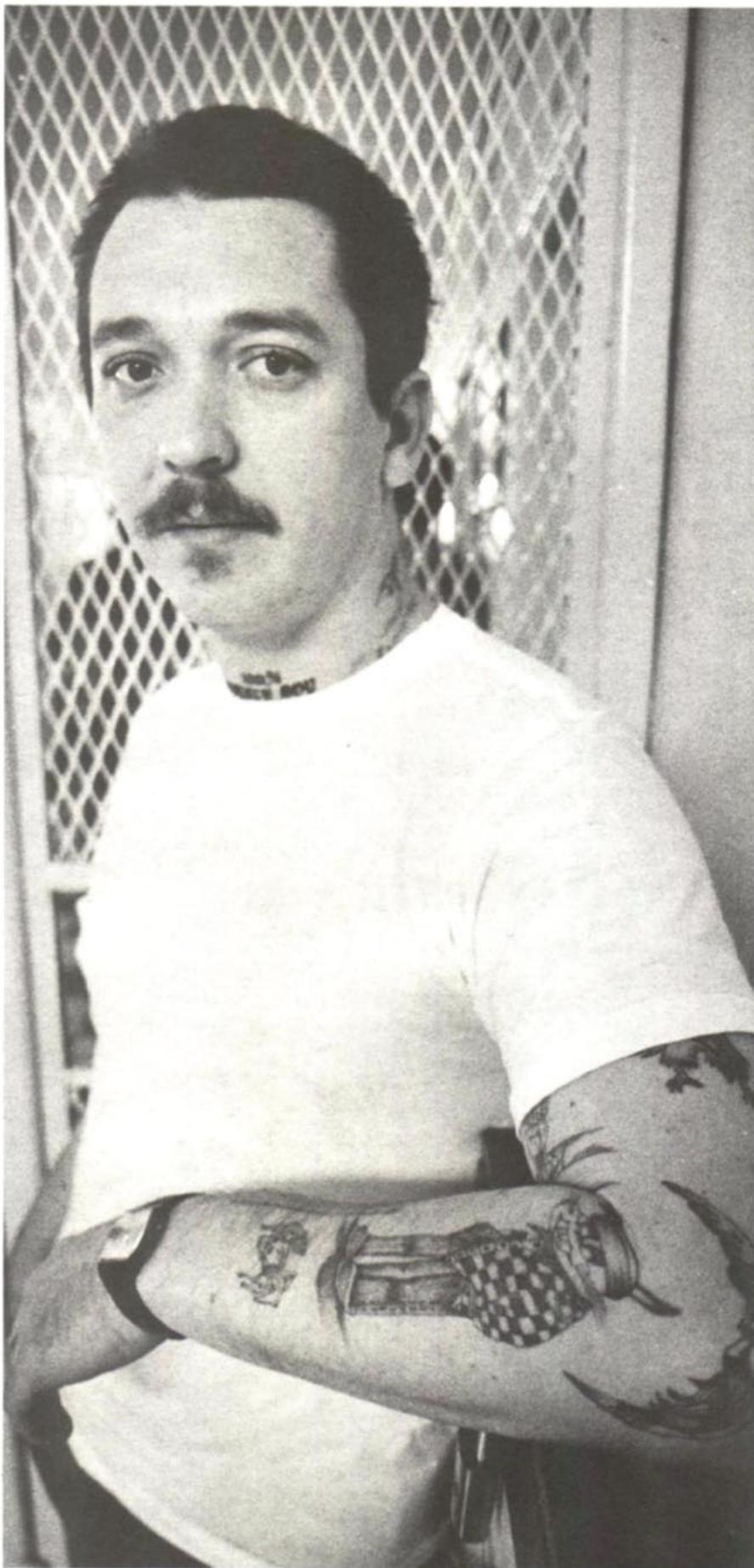


Photo by Rich Pedroncelli

Vacaville inmate Howard Dunn