

IDEOLOGY AND POLITICS IN THE CONTROL OF CONTAGION:
THE SOCIAL ORGANIZATION OF AIDS CARE

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Acquired immune deficiency syndrome (AIDS) is a contagious disease of currently epidemic proportions in several major cities of the United States. Although AIDS presents a public health risk primarily to circumscribed groups, principally sexually active gay males and intravenous drug abusers, the precise risk to medical personnel caring for AIDS patients remains unknown. When medicine becomes interlinked with a social problem, as in the case of AIDS, clinicians and researchers are reminded that biomedical information is being redefined in the larger world. The need to grapple with the social problem as part of medical reality opens the way for redefinitions of contagion risk that override traditional biomedical conceptions. Thus, risk definition and risk management in the work organization may conform more to ideological and political realities than to biomedical possibilities.

THE SPECIAL CARE UNIT FOR AIDS PATIENTS

AT SAN FRANCISCO GENERAL HOSPITAL (SFGH)

In July 1983, the Medical Special Care Unit, or AIDS Unit, was initiated at San Francisco General Hospital. The question immediately arose, how were the people who had chosen to do AIDS work handling the problem of risk? It was apparent that these persons' health risk was enmeshed in what was considered a public health threat by most citizens (USA Today, 1983). The news media frequently reported that AIDS victims had been evicted from their homes, thrown out of jury boxes, and fired from their jobs as fear of the spread of the fatal disease grew (San Francisco Examiner, June 15 1983; Wood 1983; Gallup 1983). The public felt at risk, and so apparently did many health professionals. In San Francisco, fire fighters expressed reluctance to make routine inspections of an alleged AIDS patient's apartment building, and several nurses and physicians refused to care for AIDS patients.¹ But there were three groups who definitely wanted to be involved in AIDS work:

research physicians, a group of nurses at SFGH, and many persons in the gay community.

Medical researchers at first did little to discourage the public's concern over AIDS. They admittedly used public feeling to garner support for research funding. Few citizens could object to money being spent to find the cause and cure of the disease that seemed to spread so quickly. Furthermore, researchers had a stake in the formation of a unit because drug treatment in confirmed cases of AIDS could more reliably be conducted in a setting solely devoted to AIDS care.

The gay community was anxious to see care provided to patients who had been made pariahs in many hospitals, as many patients could no longer pay for care due to job and health insurance loss. To gays, AIDS was an issue of personal concern that demanded practical attention. Providing funding for AIDS care in San Francisco offered city government a chance to gain popular support from the gay community. Gay men employed at SFGH, physicians, nurses, and social workers, many of whom had never been politically active, were coming face to face with the devastation of AIDS and lobbied for establishing an AIDS unit within the hospital.

A third group was the hospital nurses who saw the opportunity to establish a nurse-run unit that could emphasize counseling, health teaching and preparation for self-care after discharge. Nurses saw the AIDS unit as an opportunity to test such a nursing model since their attempts to establish a unit elsewhere in the hospital had been frustrated. Like many city hospitals across the country, SFGH was short-staffed and morale was poor since the fiscal austerity imposed by New Federalism. A unit staffed exclusively by RN's at a high nurse-patient ratio that would become the hub of an envisioned network of community care seemed ideal. Thirty-six nurses volunteered for

the 12 available positions.

The medical researchers, the nurses, and the gay community advanced their proposed solutions to the problem of AIDS by using the wish of public and hospital administration to isolate and confine the problem. The 12-bed unit opened and rapidly filled with very sick patients.

THE FIELD STUDY METHOD

During the first nine months of its existence, we observed the specialized AIDS ward and conducted on-site interviews with staff. Our aim, which was to discern the social aspects of risk management apart from the biomedical or even the psychological aspects, dictated an anthropological fieldwork design. We attended weekly interdisciplinary staff conferences in which medical, nursing, and social care of patients was reviewed and planned, listened to change of shift reports, interviewed staff members in groups, and held numerous informal discussions with nurses, physicians, counselors, hospice workers and visitors, and with patients and their loved ones. In conducting formal interviews, the 12 full-time registered nurses working on the unit were interviewed in depth. The interviews were open-ended and each nurse was encouraged to talk freely about his or her experience. There were several areas of questioning consistently included: previous work history, factors involved in choice to work on the AIDS unit, nature of discussion with friends and family during choice process, personal assessment of health risks on the AIDS unit, sources of information consulted, and assessment of public opinion and of the opinion of professionals in non-AIDS work. We inquired about their work on the unit and elicited descriptions of interactions with colleagues and with patients. A number of questions were asked regarding self-care and personal health. Topics raised by the interviewees were

explored, as were aspects of daily ward activity that arose during the course of the study.

We also observed the evolving patterns of practice of the research physicians. Contrary to the norm in academic medical research, physicians specializing in the investigation of AIDS treatment become actively engaged in clinical practice. Thus, when we began to hear a great deal about collaborative practice in interviews with nurses, we turned to the physicians with more specific inquiries regarding the work they do with nurses. Similarly, as the AIDS ward (and the field study) matured, other interactants came to the forefront; we found we needed to talk with hospice workers and volunteer counselors and with the public health nurses associated with the ward to put together a coherent picture of the work effort. We concurrently observed two other hospitals where AIDS patients are cared for on a general medical ward and an oncology ward. In these other settings, providers are as isolated as their patients and we wanted to compare their work to that done as part of an organized effort at SFGH. These above outlined techniques are aspects of the grounded theory methodology known as theoretical sampling (Glaser and Strauss 1967; Glaser 1978), that is, "paying special attention to selected data-yielding events, chosen on the basis of an emerging theory--a theory which evolves from the outset of the research project and is modified continually throughout its entire course" (Strauss et al. 1982).

In discussions with individuals, our emphasis was on discerning the work being done in this unique situation: the type of work, the division of labor, the way in which the workers dealt with the ever-present public and institutional scrutiny of their efforts, and the demands presented by the unfolding situation. Our reasons for this were both sociological and ethical. In the first place, despite the public interest in who "would want to work in a ward full of dying gay men" (Shilts 1984), motivational inquiry

is not particularly fruitful. The fact of the matter is that we discerned no common "psychological" pattern that brought nurses or others to the AIDS ward. The personal reasons encompass everything from obtaining particular working conditions (or even getting work at all in the current hospital nursing cutbacks), to learning new skills, to actualizing a personal philosophy, or building a career. Moreover, the individual reasons changed over time in the setting itself. For nurses, physicians and other active workers, their careers, like those in other occupations, unfolded with the contingencies presented by the situation (Faulkner 1974; Lessor 1984).

The second reason for keeping our sociological eye on the organizational process concerned protecting the privacy of our subjects. To investigate and report the evolution of the first AIDS ward by definition violates anonymity, and we are grateful to our respondents for revealing their experience so freely to us. We have attempted in the analysis to tie that experience to generalizable concepts in the study of work, that is, the social psychology, structure, and ideology of work (Berger 1964), ideology being the particular emphasis in this paper. In respect to this emphasis, Dingwall and McIntosh have commented that the word "ideology" is in no way pejorative, but rather, "For the social scientist ... 'ideology' retains its neutrality as a description of a historically and socially situated set of ideas and beliefs which is regarded by those who hold it as a true and adequate explanation of some set of phenomena and as furnishing sufficient grounds for them to plan and execute courses of social action" (1978:36). It should be iterated that this was not a verification study of "ideological positions" on an AIDS ward. Our method being much more existential in nature, our notions of the importance of ideology emerged in the analysis. What we did know at the outset was that the risk of contagion was being addressed in the medical

literature with mild reassurances and little certainty (Centers for Disease Control 1983; Department of Health and Human Services 1983), that public perception of health risk was high (Collier & Horowitz 1983), and that homophobia related to AIDS was recognizable (Clavreul 1983).

Finally, in this inquiry by participant observation, we treated our own assumptions about risk as "problematic." A methodological error easily made in fieldwork is to treat the frame of reference of one's study as if it were the organizing frame of reference of the participants in the setting. We therefore asked the generic question, What is the nature of AIDS work? Does it include risk work, and if so, what is its nature? Where does risk fit into the scheme of things?

SOCIOPOLITICAL AND MEDICAL CONTEXT

The widespread perception of AIDS as not only physical contamination but also social contamination was quickly apparent. Among the public, many were concerned and could not imagine why health workers would put themselves at risk by working with AIDS patients. Citizens telephoned the nursing staff to ask just that, or to say that they thought the nurses were "crazy." The nurses who assumed risk were presumed to be gay. During a network television interview, "non-homosexual nurse" was noted on the screen, underscoring what was presumed to be one nurse's atypical status. If one is already contaminated, one may be presumed to be at lower risk. Thus, the public assumed that primarily gay nurses and physicians would be the ones to work with AIDS patients. Although gay male professionals have been influential, they are by no means the only professionals working with AIDS patients.

The public handed a risky problem to the health professionals who were laying claim to it. Although it was costly, the public was willing to pay the price because the risk seemed intolerably high. The city allocated

\$900,000 for the AIDS ward and other public health services. The presence of AIDS influenced distribution of funds within hospitals as well. For example, at SFGH and in several other hospitals, infection control nurses had unsuccessfully tried to obtain disposable syringe and needle units that eliminate broken needles. After the AIDS news stories, the money became available. If the perception of risk continued to escalate unabated, however, it would interfere with recruiting, organizing, and getting the work done. This was observed in other departments at SFGH and in two other major hospitals. Although the AIDS experts became "risk administrators" primarily concerned with minimizing the presence of risk, at times they alternatively inflated it. When AIDS slipped from prominence in the news in Fall 1983, some AIDS workers worried that funding would be lost. (The concern with media coverage was perhaps quite realistic. Feldman [1984] has monitored the frequency of high-risk sexual practices among gay males in New York in relation to the amount of media coverage of AIDS and has found a significant positive relationship). Too much risk may be unwieldy for the entire community. When the AIDS epidemic threatened plans for the July 1984 Democratic National Convention or the San Francisco tourist industry, public health officials were obliged to deescalate the problem. The definition of risk appeared to shift with prevailing political winds.

On a more practical level, this political frame of reference and the periodically rising perception of public risk had implications for the private life of health care providers. One physician related his having to explain to his children that he was not in danger, that people outside the hospital were afraid of contracting the disease because their knowledge of it was limited. Nurses reported having discussed their decision to work in the unit with their families and friends. All had relied primarily on their

interpretation of available epidemiologic data and anecdotal data from care of AIDS patients in New York for the previous three years.² The epidemiologic findings used by AIDS workers were predominantly (1) that AIDS is mainly transmitted through sexual contact among males involving the contact of semen and blood; (2) that it is associated with sexual activity with numerous partners; and (3) that it most often occurs in persons with a history of sexually transmitted diseases and hepatitis. Thus, the gay men working with AIDS patients were able to discount risk by thinking of themselves as not being in the same "high risk group" that the public perceives. In AIDS care, internal status distinctions exist between healthy gay male nurses and gay patients with AIDS. Nurses, although sympathetic and politically active on behalf of patients, nonetheless characterize patients as "guys who've lived in the fast lane." Gay health providers clearly distinguish between being a gay male and being "actually" at high risk. On the ward, one hears most often in response to questions about risk that "not one health worker who was not in a high risk group has contracted AIDS." This information frequently serves in negotiating with family and friends over acceptable risk levels.

Under certain circumstances, AIDS work can involve social risk such as ostracism by former colleagues. Before the opening of the AIDS ward, a nursing administrator told a story about a nurse on a general medical unit who was walking past a room where a young man had just had a cardiopulmonary arrest. The arrest was totally unexpected and the ward staff were trying to decide what to do. The nurse, described as very self-assured, went in and began mouth-to-mouth resuscitation. The man had AIDS. Others joined in the code but she was the only one doing mouth-to-mouth. Afterward, other staff told her she never should have done it, and asked her how she could risk

herself and her family. Reportedly, their reaction was so upsetting that the nurse took a leave from work, and after she returned, normal relations only gradually resumed. In comparative observations in other hospitals, we saw the reluctance of some staff to give physical care to AIDS patients, such as feeding or giving mouth care. Clavreul (1983) noted similar behaviors among nursing staff in several southern California hospitals.

As the AIDS program began, there was debate in medical circles regarding the extent to which health care providers may be at physical risk while caring for AIDS patients. The Centers for Disease Control (CDC) in Atlanta issued guidelines for AIDS work similar to those that exist for handling hepatitis B (Centers for Disease Control 1982). Some hospital workers felt these guidelines provided insufficient protection. At SFGH, pharmacists would not accept return of unused unit dose packages from the AIDS ward, interns reported to the AIDS ward in full protective gear of spacesuit proportions, and phlebotomists refused to draw blood of possible AIDS patients. The nurses who had elected to work on the ward and the internal medicine physicians who had begun to treat AIDS diseases asserted that the recommended precautions of handwashing and gloving when contacting secretions were adequate. These emerging AIDS specialists determined they were not at risk, and they began teaching others about the extent of physical risk. Nurses and physicians teamed up to speak to groups in their own hospital and in other hospitals throughout the state. Risk management soon turned into an information and persuasion process.

The health professionals accepted all the help they could get as the numbers of AIDS patients grew daily. Within a few weeks of opening, the unit rarely had an empty bed. Patients were admitted with acute infections that their compromised immune systems had not been able to resist. The medical

treatment consists of a three-week trial of one of the randomly assigned antibiotics being tested. Early in the patient's illness such treatment is often effective and the patient is able to return to outpatient treatment and self-care until the next episode of infection. Most patients have four or five admissions during the course of their disease, and with each admission the infections are more severe and the patient's response increasingly weak. Although treatment has extended survival time a few months past the recorded national average, chemotherapy itself creates side effects. As a physician sadly commented in speaking of a patient, "I think we've toxified him with our pentamidine." The reality on the AIDS ward is very harsh: in the first year, nearly 100 of its patients, most of them in their twenties and thirties, died.

SENTIMENTAL WORK AND THE "DISAPPEARANCE" OF CONTAGION

In observing the type of work that claims the preponderance of staff time and attention and the beliefs that support the work, an explanation can be found for what appears to be a seeming disregard for contagion risk. The findings of Strauss and associates on sentimental work (1982) and Roth on the social organization of contagion control (1957) provide a theoretical framework for understanding the work of the AIDS unit. Strauss' group, in examining contemporary high-technology medical care, defines the task of medical work in social terms. They describe types of interactions that hospital staff members must carry out in addition to the necessary technical tasks, and how in many instances, such "sentimental work" is essential to gaining the patient's participation in treatment. They note the roots of the concept of sentimental work in the old notion of the physician's "bedside manner" or the nurse's "tender loving care," but demonstrate that the complexity of developing medical technology exacts a correspondingly complex

range of sentimental work.

If work is often as interactional as it is technical, as Strauss and his colleagues demonstrate, Roth (1957) had earlier shown that getting work done in the hospital may conform more to organizational demands than to biological laws, particularly when such "laws" are not yet completely understood. In his descriptions of contagion control measures in the tuberculosis (T.B.) hospital Roth showed that staff employed measures such as gowning and masking when it was convenient to do so and dropped them when the measures presented a barrier to friendly social intercourse with patients (1957:314). He asserted that even if general rules were formulated there would be major problems in putting them into place if the social context were ignored.

At this time, the humanistic sentimental work (Strauss et al. 1982) and comfort care that staff perform is likely to be more effective than the drug treatment. There is as yet no cure for AIDS. There is the social stigma already mentioned combined with physical suffering and severe wasting and disfigurement of young men who prided themselves on their attractive bodies. The treatment itself is arduous. All of these factors complicate the provision of care. For everyone concerned, exposure to the patients' suffering is very great. Nurses work full-time, 12-hour shifts. Volunteer support counselors see the patients daily in and outside the hospital. All research physicians see patients clinically.

Given the patients' length of stay, the amount of visits by families and friends, and the time commitment of the staff, all see a great deal of one another. The ward is a home away from home, cleaner than any in the hospital and decorated with donated artwork. "Normalizing" has been made a cornerstone of treatment. Patient rooms are filled with personal mementos; some even with coffee tables and rugs. The centrally located conference

room, that on other wards is for "staff only," is the hub of the ward. A large table covered with a fresh cloth dominates the scene. The refrigerator is stocked with snacks, and coffee and tea are available. At one end of the room are stacked cases of soft drinks, a television set and a videocassette recorder donated by the police department.

The room is shared by staff and patients except during two change of shift reports each day, and the nurses' twice weekly support group meeting led by the ward psychiatrist. Physicians, nurses and counselors review and write in charts, and patients and visitors sit and talk. New interns do their chartwork at the ward desks initially. Sooner or later, however, everyone uses the conference room, checking there first on entering the ward to learn the newest information or to give it. Patients frequently visit between admissions and tell how they are caring for themselves at home or the results of their latest laboratory tests. More often than not, there is food on the table for all, leading to the impression that the distance created by gowning and gloving for some procedures is counterbalanced by the staff's willingness to break bread with the patient.

The devastating consequences of AIDS diseases have forced people to reconceptualize the boundaries of nursing and medical care. Many new tasks have been thrust upon AIDS workers: how to do public relations, how to speak to the press, what to say to morticians, how to consult with other health institutions, how to help families cope with a son's coming out as gay and with his dying. Some tasks are even more difficult: how to talk with a patient about designating power-of-attorney and making a living will to insure that he will not be "coded" (resuscitated) when he becomes terminal. The staff feels that their sensitive interactions can only take place in a hospital and community atmosphere of warmth and caring. The prevailing ethic

is that staff members reveal themselves and their emotions to patients and to each other. Everyone is expected to tell one's own diagnosis and plan, and one's reactions and feelings. There are few taboos. One taboo is not being open to giving and receiving emotional support. The notion that to "come out" with one's feelings provides personal health and well-being stems from the gay participants' desire to normalize AIDS care, and from the therapeutic community approach pervading the nurses' orientation.

All staff have adopted "normalizing," sharing "feelings," and the notion of a therapeutic community. One physician gave a weekly running commentary during the formal care conferences regarding the trials and tribulations of a neighbor's struggles with AIDS, his family, his lover, and their negotiating with the health care delivery system. Such a case account was informative for all the assembled colleagues, and served as an implicit reminder of the human needs of the patients and of the emotional needs of the staff in their care of dying patients, patients that had become friends. The following comments of a number of nurses who talked to us about their experiences with the patients illustrate the social psychological nature of the the work:

We have taken a totally different approach because we get involved with our patients and still maintain our professional relationships. To have a patient like _____ (a man who had just visited) come in and visit everybody on the ward brings a lot of cheer and brings me a lot of humor. It's a reward, you look forward to it...I think they really know that we care, that we want to know what is going on with them...We touch them, we hug and kiss them, and sit down and listen to their woes since they've seen us last: "Guess what's happening in my life, my landlord is trying to kick me out, my family is having fits, my friends won't talk to

me...We counsel them, we hook them up with other people who can help, we listen...We get to know them very intimately. We really know them. And it's a wonderful feeling being known that way by someone.

Quite clearly there are rewards for staff as well as satisfactions for patients in providing such care. A physician, self-described as one who always "avoided the psychiatric business at all costs," allowed that while the drug therapy investigation was exciting, the unexpected satisfaction had been becoming involved in holistic care in collaboration with nurses, counselors and others sharing an equal level of interest. For all concerned, the social closeness demanded by the work mitigates the physical distance demanded by anticontamination procedures.

THE IDEOLOGY OF SENTIMENTAL WORK IN AIDS CARE

"Success" in AIDS care relies more on the application of sentiment than of technology. Strauss and associates (1982) have described seven types of sentimental work done by health professionals in the technologized hospital; some of this work is done on the AIDS ward. Interaction that promotes personal identity and awareness of the patient's cues regarding his readiness to discuss dying (Strauss et al. 1982:263-265) are two types of sentimental work prominent on the AIDS ward. Strauss and associates touch on another type of sentimental work in the hospital: interaction concerning the breaking of moral rules. Their theoretical concern is the violation of the small, almost implicit everyday moral rules that govern interaction. Violation of these moral rules frequently occurs in hospitals. For instance, health professionals being brusque, leaving without warning, or interrupting another's conversation. They point out that this situation necessitates that staff orient the patient to the hospital culture and give warnings and

explanations, a type of sentimental work (1982:258-259).

The question of violating moral rules surfaces in AIDS care not only in a person-to-person way, for AIDS patients are subject to the potential insensitivities of hospital culture and routine much like any patient, but in terms of the perceived influence of the larger moral order of society. The presence of the AIDS patients' disease is a reminder of stigmatized status, that at least in some quarters of straight society constitutes in itself a violation of the moral order. Our data are replete with examples of the continuing presence of this moral context. An infection control nurse, who telephoned from an East Bay hospital for advice she could give to reluctant hospital plumbers, relayed the plumbers' comment, "It's not really being afraid of getting AIDS, but if you got it everybody would know you were gay." Such responses reflect public concern over social contamination in much the same way as do debates over whether gay persons shall be allowed to be scout troop leaders or school teachers (Cf., Grieg 1984; Bancroft and Shilts 1984).³ This powerful social context is quite simply ever-present and presents a barrier that must be symbolically broken by AIDS workers if care is to be seen as "humanistic" and "holistic." The patient's personal identity can only be protected and preserved if that identity is seen as legitimate, and one significant aspect of identity is the patient's gayness. Thus, AIDS workers must either suspend the ordinary moral rules or actively assert that those rules are wrong. Under either condition, it then becomes possible to carry out sentimental work. In the case of the former, the staff member is apt to make a comment such as the following: "I'm not here to judge...It is a privilege working here. The work is personal and you can get involved with the patient and family." In the case of the latter, the comments of a gay male worker are illustrative: "I want to take care of

these men. They are friends and brothers...Any fear I have doesn't come from working here, it comes from being a gay male in our society. There is a great deal of fear in doctors and nurses (elsewhere). I worked (in other places) before the unit was set up and I saw some awful things." Thus, whether staff suspend the moral rules, or, attempt to rewrite the meaning system, an ideological position is taken. Furthermore, it matters little whether persons were recruited into the work with this point of view; in order to carry out sentimental work, they become converted.

To meet psychosocial needs, to do identity work, family work, or any type of sentimental work, the patients (and their milieu) must be socially decontaminated. In the social decontamination process, it would appear to the world that the putative AIDS agent is believed to disappear in the face of warm and caring social interaction. Roth found that when staff in the T.B. hospital socialized with patients they never wore masks or assumed other protection against contagion, leading Roth to comment that there seemed to be a widespread belief that the tubercle bacillus adheres to business hours (1957:314).⁴ The comments of an infection control nurse working with AIDS illustrate our intuitive human appreciation of the increasing psychological distance that elaborative protective clothing creates. She noted that she discourages nurses throughout the hospital to wear masks while caring for AIDS patients on their wards: "They don't need them because it's not an airborne infection, but they really shouldn't wear them because covering the mouth cuts off communication and makes the patient feel isolated and even more alone."

Staff in the T.B. hospital sometimes dropped contagion control measures in order to get the work done (Roth 1957: 310). This is also the situation in the AIDS ward: barriers are dropped in order to get the work done. The

work, however, is expressly "sentimental," as the Strauss group have described occurring in the "technologized hospital" (1982). A third explanatory concept, ideology, surfaces from the AIDS data. For without a belief system, a way for practitioners to explain to each other and to outsiders the importance of the object of their work, and therefore their work, it could not be effectively carried out.

DISCUSSION AND CONCLUSIONS

Knowledge about AIDS has grown substantially in the past year, and the professionals at San Francisco General Hospital have made a major contribution. But much, including the risk of contagion in AIDS care, remains unexplained. The passage of time offers reassurance. As of August, 1984, the Centers for Disease Control (CDC) in Atlanta report that "so far there have been no known cases of acquired immune deficiency syndrome (AIDS) being transmitted to health care workers who are involved in the care of AIDS patients" (American Nurse 1984:23). The statistics are encouraging to workers, in spite of the lack of medical certainty. As one medical researcher heavily involved in clinical work with AIDS patients candidly remarked, "let's face it, we really don't know how much at risk we are...you don't really start out by thinking about it in those terms. You see a couple of patients, your involvement grows, the patient load goes up, and before you know what happened, you're into it...you didn't really plan it. Now you've probably been as exposed as you possibly can be anyway." Similarly, the nurses who staff the AIDS ward, in spite of all their advance planning, were at times surprised in the early months to find themselves in the midst of so much physical disease and patients needing so much bodily care, the reminder of potential contagion. Our individual interviews confirm that at times staff think about risks and may become briefly fearful for reasons they

cannot always articulate. Their responses are not unlike those of other workers exposed to risk. Flight attendants reported in answer to questions about fear of crashing, "well, sometimes you just have a 'squirrely' (uneasy) day, but you're on the ride, you just see it through" (Lessor 1982). Similarly, these professionals working with AIDS patients have chosen their path of work, and the work is sufficiently exciting and rewarding for them to "see it through." Occasionally, specific instances may elicit staff fear, such as an accidental puncture from a needle used on a patient. Nurses and doctors have reported that they did what they could--"made it bleed," "prayed," "had faith"--but also relied on their knowledge that getting stuck with needles has always been an occupational hazard and therefore one that other AIDS workers throughout the country must have been exposed to for some time.

The point is that certainly AIDS workers think about personal risk on occasion; they do so to the same extent that anyone whose job presents risk thinks of it. For the most part, people are too busy doing the job to be absorbed in much else, and the job is providing care to AIDS patients. While, as we have seen, effort is directed toward research and testing, "success" with patients is measured in terms of creating a network of care--teaching self care, providing home care, training a variety of community workers and volunteers to help, bolstering the patient's social network of friends and mending family ties to provide support, and making the way for the patient's dignified death. Politics and ideology are essential ingredients in creating conditions that make the work possible. Politically, AIDS workers have leveraged power, often that of their professional expertise, in order to get what they needed to carry out their work. Moreover, an ideological position that asserts the patient's humanness relies on the removal of ascriptions of stigma or "social contamination." In the

course of expunging social contamination, it is likely to appear that staff have disregarded all concern for contagion.

Roth observed that seemingly irrational procedures in T.B. care grew out of man's uncertainties regarding the laws of nature. The ritual and magic were man's laws. We are no more certain of nature's laws with respect to AIDS and, in addition, experience conflict and doubt over society's norms regarding homosexuality. In the context of these uncertainties, 'man's laws,' to use Roth's term, may be ideological and political as well as ritualistic and magical.

NOTES

¹May through July, 1983, Lessor collected data in interviews with civil service and hospital workers in a pilot study for the investigation reported here. However, we first became aware of "AIDS anxiety" during an earlier study of employee conceptions of occupational health (conducted from October, 1982 to April, 1983). When questioned as to their greatest on-the-job health concerns, hospital workers frequently listed exposure to hepatitis B and to AIDS as a "new worry." Nurses explained that they had previously worried most about psychological burnout or back injury, or in many instances chemical exposure, but not contagion. We thank Barbara Burgel for her comprehensive field notes on this subject.

²Although AIDS was not reported in the medical literature until 1981, nurses at SFGH were reassured to learn that nurses on the east coast had safely cared for AIDS patients for periods of time longer than the presumed incubation period of the disease. Nurses shared information informally and in conferences such as those sponsored by the Department of Nursing, National Institutes of Health, Clinical Center, in 1983.

³We are indebted to Robert Dingwall for pointing out this feature of

social contamination.

⁴Further illustrating the relationship between physical and social barriers, Lessor found in a field study of the tuberculosis hospital that when hospital staff wished to emphasize their social distance from non-white, poor and otherwise "deviant" patients, they took great pains to establish physical barriers; furthermore, wearing masks (or more often, making the patient wear a mask) bore no relationship to the patient's established degree of contagion (whether or not he had a positive sputum for tubercle bacillus) (Lessor 1969).

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ABSTRACT

There is as yet no cure for acquired immune deficiency syndrome (AIDS). State of the art care, such as currently practiced on the first AIDS ward, primarily involves psychological and interpersonal care and considerations. As a disease suffered principally by gay males, AIDS is symbolic of deviance that contravenes society's moral order. To provide emotional comfort, AIDS workers must remove ascriptions of social contamination. In doing so, particularly in the face of medical uncertainty regarding the precise risk to health providers, it may appear to the casual observer that AIDS workers are more concerned with ideological and political definitions of risk than with biomedical risk.

[KEY WORDS: Acquired immune deficiency syndrome (AIDS), contagion, politics of medical care, stigma]

AIDS

Community Outreach

by Jeff Miller and Lisa Bain

It all started with a 1981 phone call from a New York dermatologist to Marcus Conant, a professor of dermatology at UCSF, reporting an outbreak of an extremely rare form of cancer called Kaposi's sarcoma (KS) and a virulent form of pneumonia called *pneumocystis carinii pneumonia*. Intrigued by the outbreak of a disease seen primarily in Europe among elderly Italians and Jews and in equatorial Africa among young blacks, Conant asked his colleagues if they had seen any cases. Sure enough, one had. The patient was a young man, who, like all of the New York cases, was homosexual. Conant expressed his concern to William Epstein, chair of the Department of Dermatology. "I felt that with one of the largest gay communities in the world in San Francisco, we'd be smart to start a clinic, look for cases of Kaposi's sarcoma, and start studying the disease." With Epstein's support—but without any funding—the KS Clinic at UCSF's Ambulatory Care Center opened in July 1981.

That was the beginning of a remarkable collaboration between physicians and scientists in San Francisco and across the country. Their goal: to identify the agent responsible for a mysterious suppression of the immune system and to find an effective way to combat it. It was a daunting task. Associated most closely with gay men and apparently spread through bodily fluids, the disease—soon to be known as AIDS (Acquired Immune Deficiency Syndrome)—was also found in Haitians, hemophiliacs and intravenous drug users. Its origin was unknown; its onset sudden and unexplained; and its effects deadly.

Yet, despite a total number of cases that quickly surpassed those of Legionnaire's disease and toxic shock syndrome, the epidemic failed to stir national public interest or demands for action. Worse, some dismissed the epidemic as divine punishment for an immoral lifestyle.

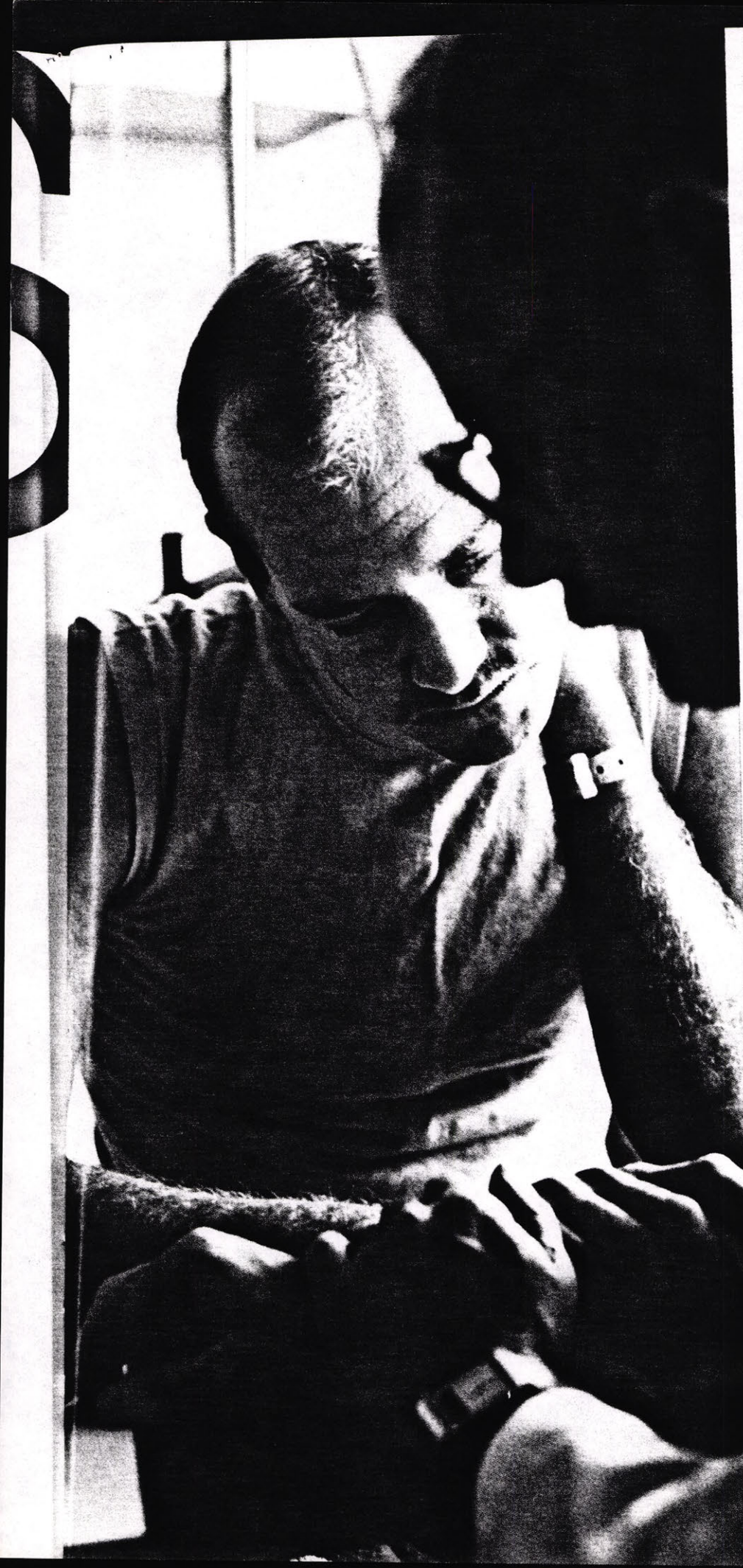
The UCSF response was considerably different.

By the end of 1981, 50 UCSF physicians and scientists from all four schools and its two major affiliates at SFGH and the VAMC were already working to unravel the AIDS

mystery despite a continued lack of funding. There was also close cooperation with the Center for Disease Control and National Institutes of Health. In the clinics, doctors volunteered their time. Epidemiology was done gratis. Some of the other research was "piggy-backed"—scientists involved with other projects did AIDS research during extra time. Perhaps even more important, representatives from disciplines that usually did not collaborate—dermatology, oral surgery, pharmaceutical chemistry, blood banks, pulmonary medicine, medical anthropology, psychiatry, oncology, immunology and infectious disease—began meeting weekly. "The meetings got to be absolutely electric," says John Ziegler, an oncologist at the VA Medical Center familiar with KS cases in Africa, "and Marcus Conant deserves the main credit."

Convincing the federal government and others that AIDS was an urgent public health problem proved more difficult. That began to change early in 1982 when the American Cancer Society granted \$50,000 for one nurse's salary at the clinic. The following year, UCSF received its first federal money—\$450,000 in all. And with the help of Willie Brown, speaker of the state assembly, more money was forthcoming from Sacramento in 1983. A University peer review committee was established to review the various AIDS research projects, and, despite some early disagreements over the allocation of funds, research at UCSF and other UC campuses began to accelerate. Last November, 14 projects at UCSF received another \$625,000 from the UC task force for AIDS research.

Even before funds were in place, the medical sleuthing at UCSF had yielded some important clues. In December 1982, pediatric immunologists Arthur Ammann and Morton Cowan treated a 20-month-old baby who had an unusual infection. The baby had received multiple blood transfusions at birth. Ammann, with fellow immunologists Daniel Stites and Donald Abrams—who later moved to SFGH to be assistant director of the AIDS Clinic—had been studying the abnormalities in subpopulations of cer-



Hope—and realism— on Ward 5B

For 31-year-old Michael Overstreet, being diagnosed with Kaposi's sarcoma and hospitalized with pneumocystis pneumonia—all in a matter of a few days—was not so much a surprise as a confirmation. "I had been sick for about a year so the possibility of AIDS had crossed my mind." Nor was he bitter. "I haven't gone through the why-did-it-happen-to-me phase because I know exactly why. I've been around in my time."

There have been some surprises, though. Finding so many new ways to lie in bed is one; the quality of care still another. "When I first came on the ward I was nervous. I had never visited anyone here and I didn't know what was going to happen to my body. But the care I have received here has been great. The people are warm and kind. No one is afraid of touching me. There's a real sense of family."

Being able to make decisions about his care—such as whether or not to take a new drug for his pneumonia (he did)—is important to Overstreet. So is the time he has spent reflecting on his diagnosis. "The hardest thing for my friends to accept is that I probably won't be around for some of the things they're planning. The hardest thing for me is that I just won a major custody fight for my 12-year-old daughter. It's hard to think I'm not going to be around to protect her. I don't know what to tell her."

Overstreet is more certain about his plans once his pneumonia is cured and he leaves the hospital. He wants to do volunteer work to educate people about the disease. "There are people out there who know they have the disease who are still screwing around. They have to be made to understand they can infect a lot of other people."

Despite his situation, Overstreet is more philosophical than depressed. "I believe you live life to do the best things you can, to leave some kind of goodness behind. I write music, and that music will be here no matter what."

J.M.

Michael Overstreet with nurse Bill Barrick.

tain immune cells called T-lymphocytes. That work led them to recognize similarities between the baby's immune function and that of AIDS patients. With Herbert Perkins of the Irwin Memorial Blood Bank, they traced one of the transfusions to a blood donor who had subsequently developed AIDS. This, the world's first transfusion-linked case, gave firm support to the notion that AIDS was caused by a transmissible agent.

Shortly after that case, Ammann and Cowan noted immunodeficiency in the child of an intravenous drug user. Eventually, they determined that the mother was an AIDS carrier, although she herself was only partially immune-deficient. She had passed on the disease to all four of her children. Never before had transmission of an infectious disease to several consecutive children been shown.

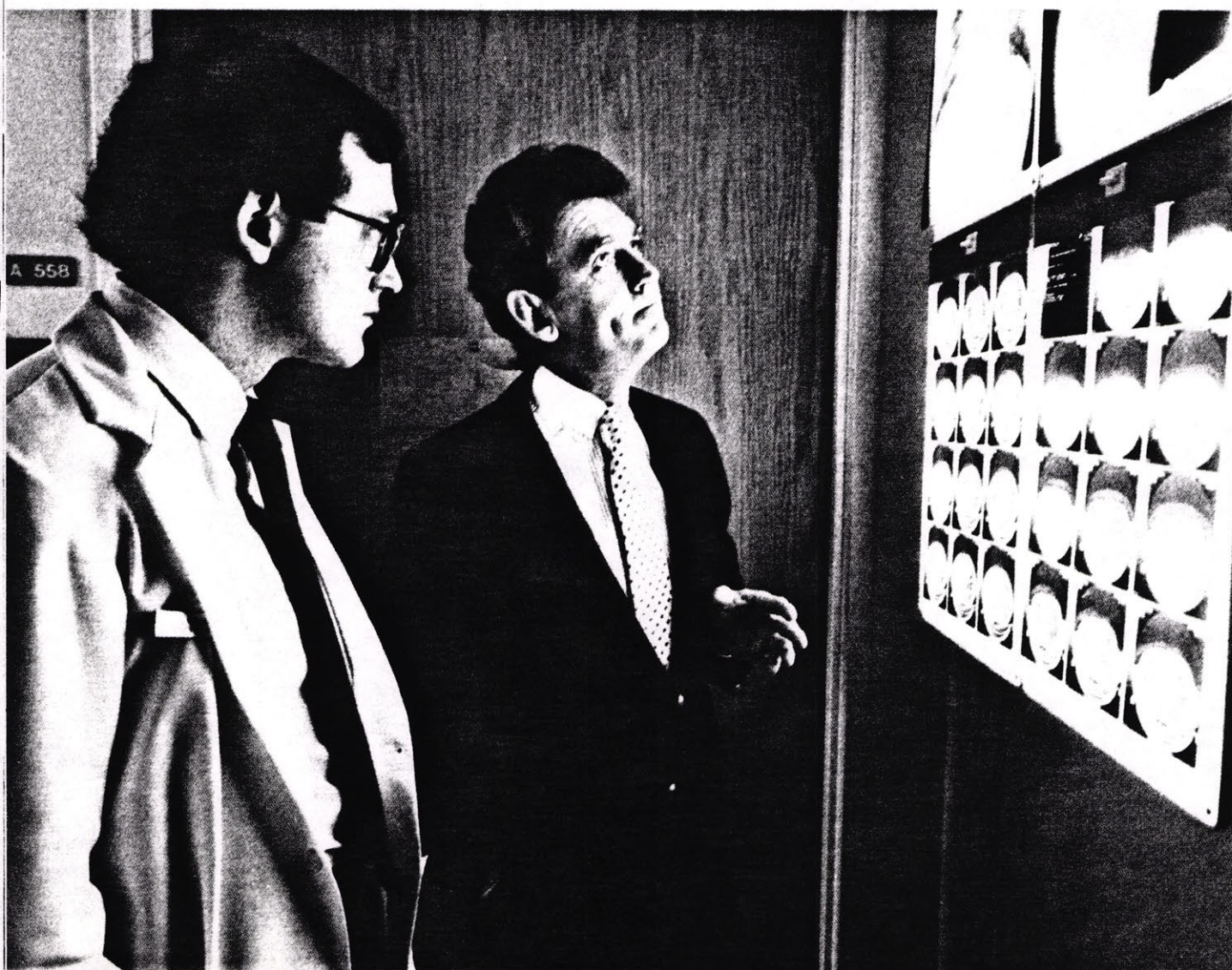
While Ammann and the others were busy on the Parnassus campus, clinical research trials were being conducted at SFGH, where outpatient treatment had been centered. The trials focused on KS and included studies of alpha-interferon, gamma-interferon and interleukin II. In the process, a jointly used tissue bank was set up on the Parnassus campus under the direction of oral pathologist John Greenspan.

As 1983 wore on and the number of AIDS cases rose, the cause of the disease still eluded medical investigators. Despite the slow progress, UCSF clinicians and researchers from epidemiologist Andrew Moss to psychologist Lydia Temoshok to oral cancer specialists in the School of Dentistry continued their combined attack on the problem. And John Mills, chief of the infectious disease department at SFGH, together with Lawrence Drew, director of clinical microbiology and infectious diseases at Mount Zion Hospital and Medical Center, continued probing the suspected role of cytomegalovirus infection as a cofactor in the development of AIDS.

By the beginning of last year, scientists were closing in. In May, UCSF virologist Jay Levy, working with modern cell-culture methods, reported finding evidence of a previously unknown virus in the blood of AIDS victims. A short time before, scientists at the NIH and the Pasteur Institute in Paris had used different scientific names to describe similar findings, confirming to a large extent what had long been suspected — AIDS was probably caused by a virus.

The research findings suggested that many gay men are exposed to the suspected virus, but that other factors must

Harry Hollander and Marcus Conant at UCSF AIDS Clinic.



Questions and Answers

Question: I am taken with the repetition of the thought that price is the driving force in this whole equation. Having been brought up on the idea that quality will be remembered long after price is forgotten, I would like to ask you who is going to be responsible for maintaining some kind of quality in medical and hospital care delivery?

Dr. Lee: I would say that the problem is that right now we do not have a public agency with an overarching concern with the whole system. The Health Care Financing Administration is only interested in controlling Medicaid costs and cutting the rate of increase of government expenditures. The medical profession in the past has had the responsibility for quality assurance. We are going to have a very hard time in the next five to ten years, as the incentive changes significantly in terms of price versus quality. There isn't in the system now the built-in incentives for quality that there used to be. So, I share your concern.

Question: Do you see any signs that, with new technology, the cost of medical service will actually decrease?

Dr. Lee: As you develop these new ideas, not only does the cost not go up, it gets wiped out. We spend much less than we used to on polio. We save as much in one year from the capacity to keep people from getting polio as we spent altogether in developing the knowledge which made it possible to do polio research. Until society basically says we don't want to be cared for any better than we are now, that we don't want to be able to walk, that we are willing to sit in our wheelchairs, then we are going to do hip replacements. Until society says let people without kidneys die, we are going to do transplants and dialysis, even though they are very expensive.

Mr. Kerr: The problem of a price-driven competitive environment, from the vantage point of a hospital, is the basic assumption that the price is based on comparable service. The reality is that the cost of patient care delivery in this institution is legitimately higher because of the more intensive patient population we care for.

Unfortunately, teaching hospitals provide a disproportionate share of uncompensated care, have the sickest patient population, have the research and teaching costs I just mentioned, and yet are expected to come up with a price that is comparable to the individual institution down the street that doesn't bear these responsibilities.

Question: Regarding the change in the rules as far as Medicare is concerned: If it is a fixed price for a certain operation, I got the impression that in some instances those who come in might be kept longer than others. Will you make up on the bananas what you lose on the peaches?

Dr. Lee: It is a fixed price, not just for the procedure, not just for surgery, but for the care of the patient during the entire period he or she is in the hospital.

At the moment the Health Care Financing Administration is being generous with respect to the teaching hospitals' reimbursement levels. In four years, though, they will set a national rate, and we are going to find ourselves competing for a heart patient who needs bypass surgery with hospitals in the south that have much, much lower costs.

We now have a fairly good level of reimbursement, and we also have a teaching subsidy and the medical education pass-through. This may be eliminated within a few years, as the Medicare deficit looms larger, and the politicians don't want to increase access barriers for the elderly.

Dr. Altman: My concern is that, as we get into this further, the hospitals that are going to be losing money on certain of these diagnostic groups are going to say, "Let's stop doing this." Those patients then are going to be shifted here. And the patients who look like losers are going to be shifted here as well, because historically this place has always had a big open door. I would hate to think that we would have to start thinking, "Let's not take this patient on Friday afternoon because we are looking at the weekend when we can't do very much, and it's going to mean three more days at \$700 a day—money that won't be reimbursed."

Question: I am impressed to hear how this competitive cost squeeze is militating against the federal policy which was supposed to encourage general internal medicine and discourage high specialization. What has this done, for example, to this school's very progressive family practice enterprise?

Mr. Kerr: That's the kind of program which is going to be in greatest jeopardy, because family practice is a heavily outpatient-oriented educational program, and it is in the outpatient department that you lose your shirt. And, as the global expenses of, let's say, a university system are examined, someone is undoubtedly going to say, "Let's cut those areas where we are losing our shirt."



be present in order for the disease to develop. In September 1984, Chiron, an East Bay genetic engineering firm, announced it had cloned the genes for the virus in collaboration with Levy's lab, creating at least the possibility of a vaccine, but not in the immediate future.

That announcement followed by about a month the report of a study, headed by John Ziegler at the VAMC, of 90 homosexual men with non-Hodgkins lymphoma—fast-growing tumors in the bone marrow, central nervous system or abdomen. "It is now clear that the lymphoma is another malignancy to become linked to the AIDS epidemic," said Ziegler.

More recently, Jeff Golden and Daniel Santi reported on the use of a promising new drug for treatment of the opportunistic pneumonia associated with AIDS, and the School of Dentistry's Deborah Greenspan also reported finding a new type of lesion in the mouth of male homosexuals. The lesion may provide an early clinical link to the later development of AIDS.

But research was—and is—only one part of UCSF's amazing response to the deadly AIDS epidemic, which, by November 1984, had begun to show up in isolated heterosexual patients who were not part of the four high-risk groups. As the number of patients increases, primary care becomes even more important.

In August, UCSF further expanded its patient care service, begun with the pioneering KS Clinic, by opening an Adult Immunodeficiencies Clinic on the main campus under the direction of Harry Hollander. AIDS patients referred to the clinic by physicians in the community are offered not only special medical support, but also the services of social workers, nutritionists, respiratory therapists and other health professionals. But the most remarkable development was at SFGH, where, after much anguished discussion, the doctors decided to open a special AIDS ward.

Considering that the inpatient ward was once a lightning rod for criticism, its success—and planned expansion to 24 beds—is very satisfying to oncologist Paul Volberding, chief of AIDS Services at SFGH, who originally proposed it. Infectious disease specialist Constance Wofsy, who is co-director of the AIDS Clinic, participated in the planning.

Said Volberding, "In 1983, we already had eight to ten AIDS patients here, but they were scattered all over the hospital. It was difficult for doctors and nurses to provide sensitive care. We felt we would do better if these patients had private rooms in the same unit where everything could be coordinated."

Still, the initial reaction to Volberding's suggestion was almost "uniformly negative," he recalls. "Merle Sande [chief of medicine at SFGH] was one of the few who was very receptive."

Clinical nurse specialist Cliff Morrison—whom Volberding commends for his effort in moving the ward idea from "the general to the practical" and for recruiting a "tremendous nursing staff"—was one of those with serious reservations. "At the time I felt strongly that isolating AIDS

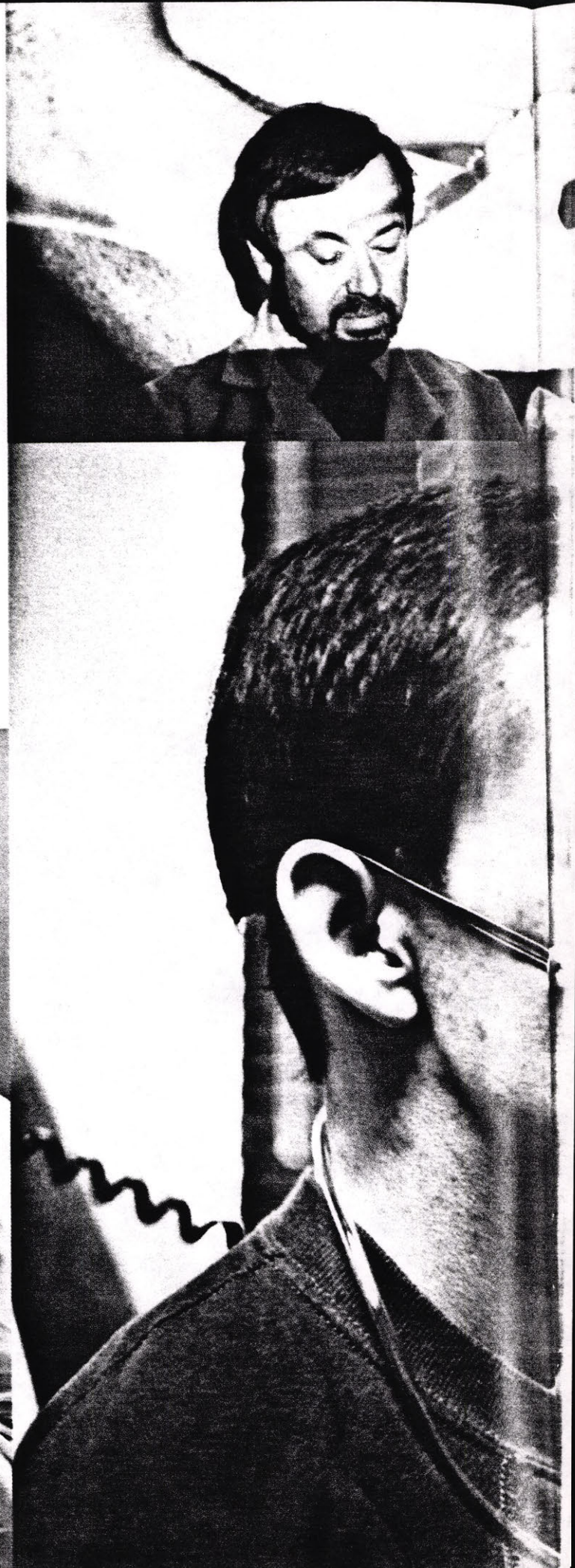
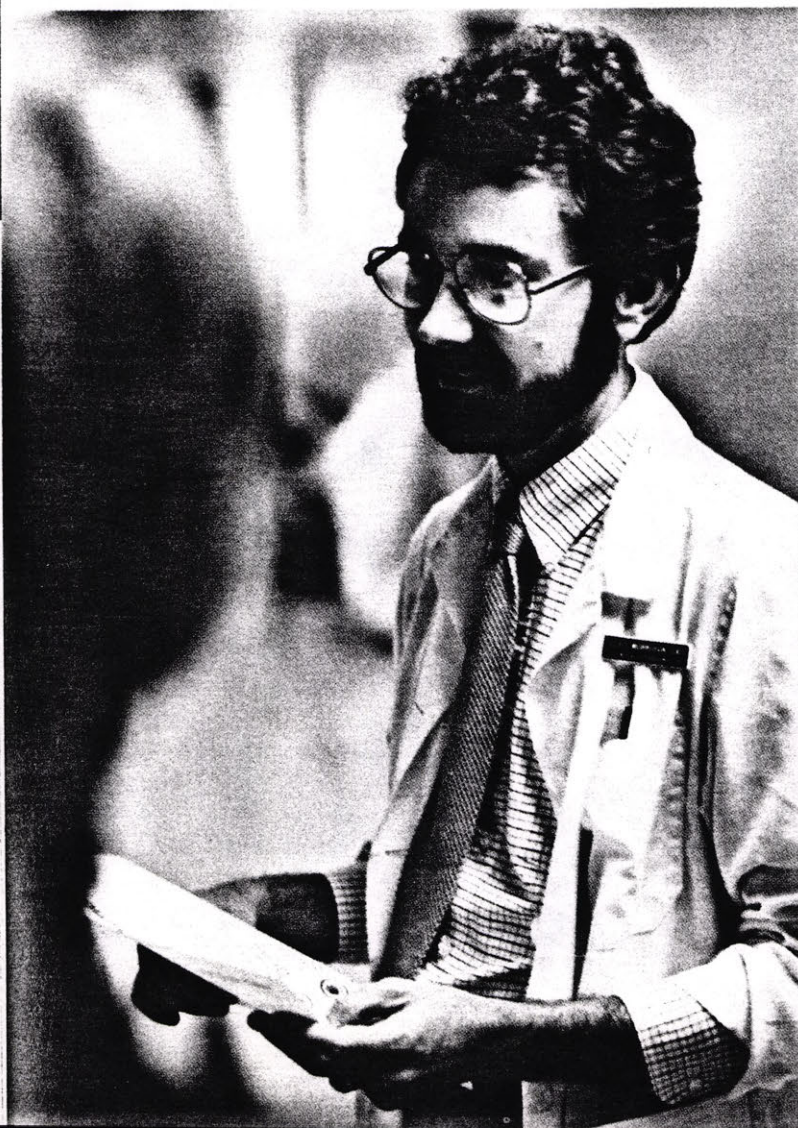
patients could result in a 'leper colony' atmosphere that could in turn reinforce all the negative attitudes about homosexuality," says Morrison.

But it has not turned out that way. In large part that is due to the way the patients are treated. Patients are encouraged to set their own visiting hours, decide who should be allowed to visit (family members and lovers can stay overnight), and approve and be knowledgeable about their course of treatment. They are also urged to seek legal advice about writing their wills and generally to confront the reality of their diagnosis as best as they can.

"Most of the patients are not afraid of death. They're afraid of dying. They don't want to be alone. They don't want to be in pain. And they want to be in control of their lives as long as possible. The ward gives them all of that," Morrison, who became coordinator of the unit, explains.

Few, if any, of those involved with the treatment of AIDS patients remain unaffected by the experience on the ward. "Here you have young, vital people struck down in the prime of their lives with a usually fatal illness. It's a special

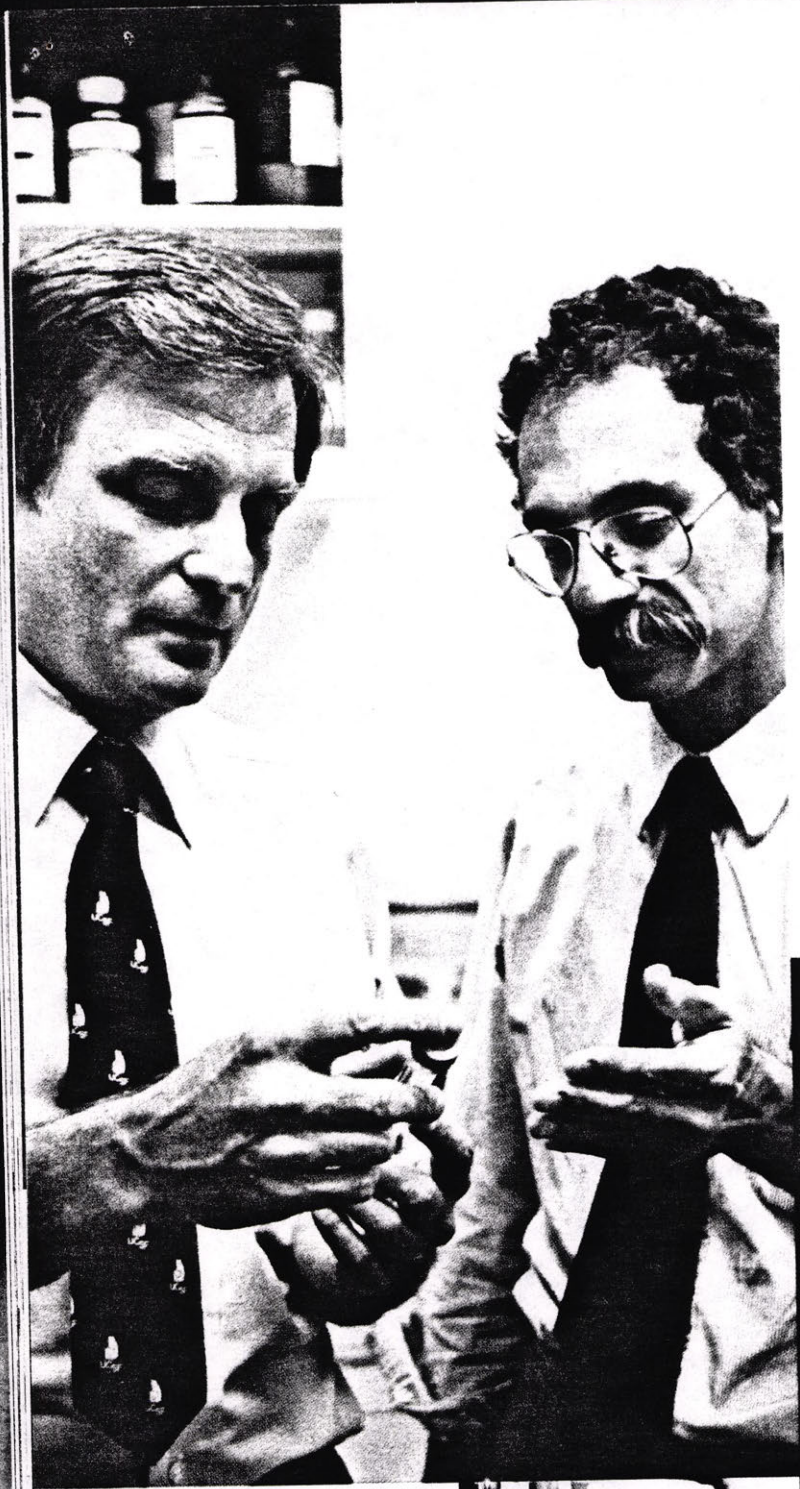
Below, nurse Cliff Morrison; above, researchers John and Deborah Greenspan; right, clinic director Paul Volberding examines AIDS patient.





*"After much anguished discussion
the doctors decided to open a special
AIDS ward."*





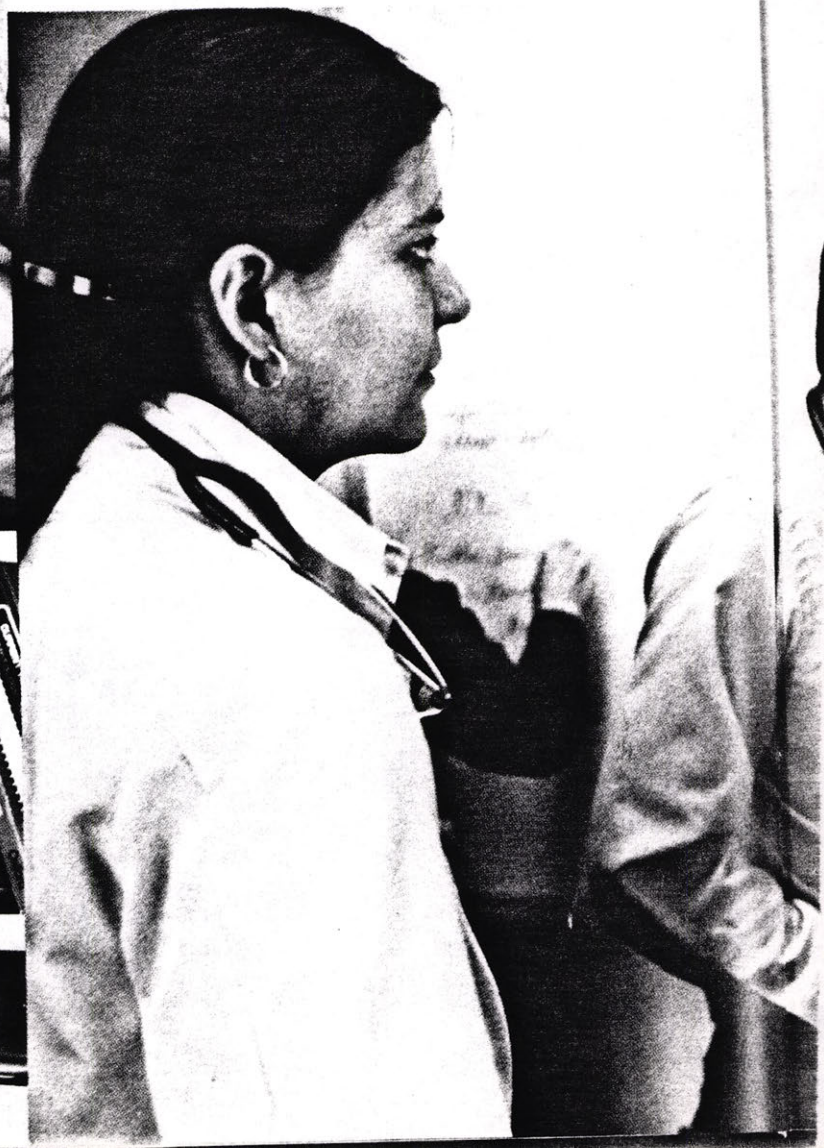
tragedy," says Jon Fuller, a resident at SFGH who has treated several patients on the AIDS ward. J.B. Molaghan, a nurse practitioner at the AIDS Clinic at SFGH, has a similar perspective. "Many on the clinic staff are gay, which creates a lot of empathy and a lot of personal interest in the patients."

Alison Moed, head nurse on the AIDS ward, agrees. "We become part of the people we care for."

The close relationships are probably inevitable. As Molaghan explains, AIDS patients must deal not only with a fatal diagnosis, but sometimes with the loss of their job, friends and home. "Patient care here is—and has to be—more than treating symptoms. We're forced to get involved in a person's life, to deal with social agencies and landlords. It's impossible to separate our feelings since patient problems become our problems, too."

For the ward staff, that involvement often extends to family members, many of whom may not be aware a son or brother is gay until he has been hospitalized with an AIDS-related disease.

Upper left, pediatric immunologists Arthur Ammann and Mort Cowan; below left, Donald Abrams at SFGH; below, resident Sandra Hernandez and nurse J. B. Molaghan at the SFGH AIDS Clinic; right, epidemiologist Andrew Moss and Constance Wofsy, SFGH Clinic codirector.



Complicating matters are the diagnostic tests themselves. Says Molaghan, "We don't have a test to diagnose AIDS without specific symptoms being present. So we have to tell the patient, 'Right now there's no evidence of AIDS. We'll have to follow you closely.'"

But what does that mean—that they don't have AIDS? Or that they may get it? It's very frustrating."

Once the signs of physical deterioration are obvious, "You go through a tremendous emotional drain," explains Tracy Moran, oncology nurse at the AIDS Clinic for the last two years. "You cry a lot, and you laugh a lot, because many of the patients have an incredible sense of humor. And they can be so brave. One in particular has been such an optimist throughout his illness. He never believed he was going to succumb. 'I'm going to beat this thing,' he always told us. Unfortunately, he's not."

For Morrison, the stress is cumulative. "Sometimes you have to sit down and let out all the emotion. I'm only 33, but in the last year and a half, I've watched over 100 people die. One of them was a close friend."

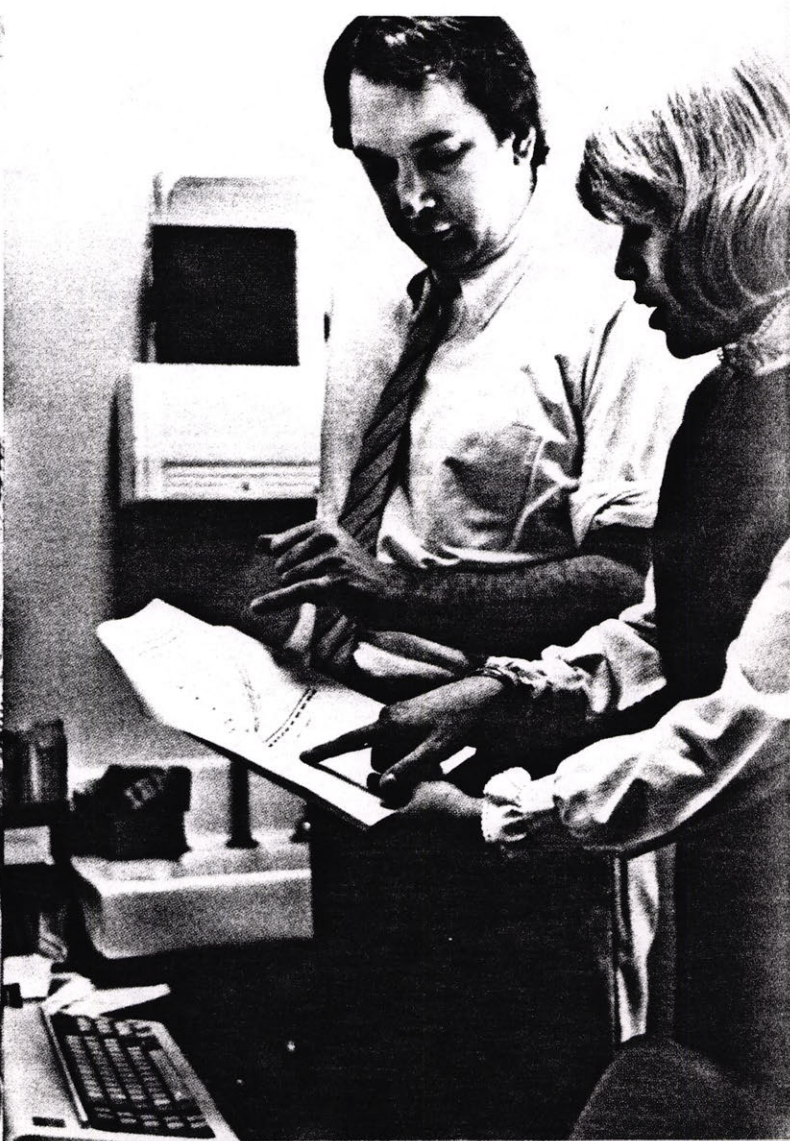
Regular group sessions with a facilitator allow the staff at both the ward and the clinic to vent their feelings, fears

"We become part of the people we care for."

and complaints. Informal talks between various staff members are also important, as is strong support at home. "People with home problems couldn't survive here," says Morrison.

Despite the difficulties, turnover and burnout are infrequent. The original nursing staff on the ward is virtually intact, says Morrison, who recruited most of them after long interviews that dealt not only with their philosophy of health care but also with their sexual orientation. Half of the ward staff is gay. "There's an optimistic mood and a strong esprit de corps among the staff because no one works on 5B [the AIDS ward] who doesn't want to."

Indeed, the atmosphere at both the ward and the clinic is upbeat, the faces friendly and reassuring. There is



laughter and a good deal of efficient bustling down spotless corridors. There is also a palpable sense of purpose. "Sometimes people use the clinic as an emergency room because they feel more comfortable here," says Molaghan. "The script changes every day."

Thanks to a multidisciplinary staff of 40, the clinic is equipped to earn that trust and to react to changing circumstances, despite an average 1,200 patient visits per month.

The same flexibility is true of the AIDS ward, where counselors, social workers, a dietitian, a psychiatrist and volunteers share responsibility for overall care with doctors and nurses. Rather than cause conflicts, the multidisciplinary approach has won the plaudits of people such as head nurse Moed. "The more you work here, the more you realize you have to be here. You also appreciate the fact that AIDS patients receive the kind of care every patient in every hospital should receive."

While the research and clinical activities at UCSF have provided an important resource for those stricken with this deadly disease, disseminating the knowledge not only to the local community, but around the country, has been an equally important task. Merle Sande headed a task force which included infection control expert John Conte and representatives from all three hospitals. It developed infection-control guidelines reported in the *New England Journal of Medicine* and now in use in hospitals nationwide. Conte and his staff also began to speak to hospital staffs all over the country on the appropriate precautions hospi-

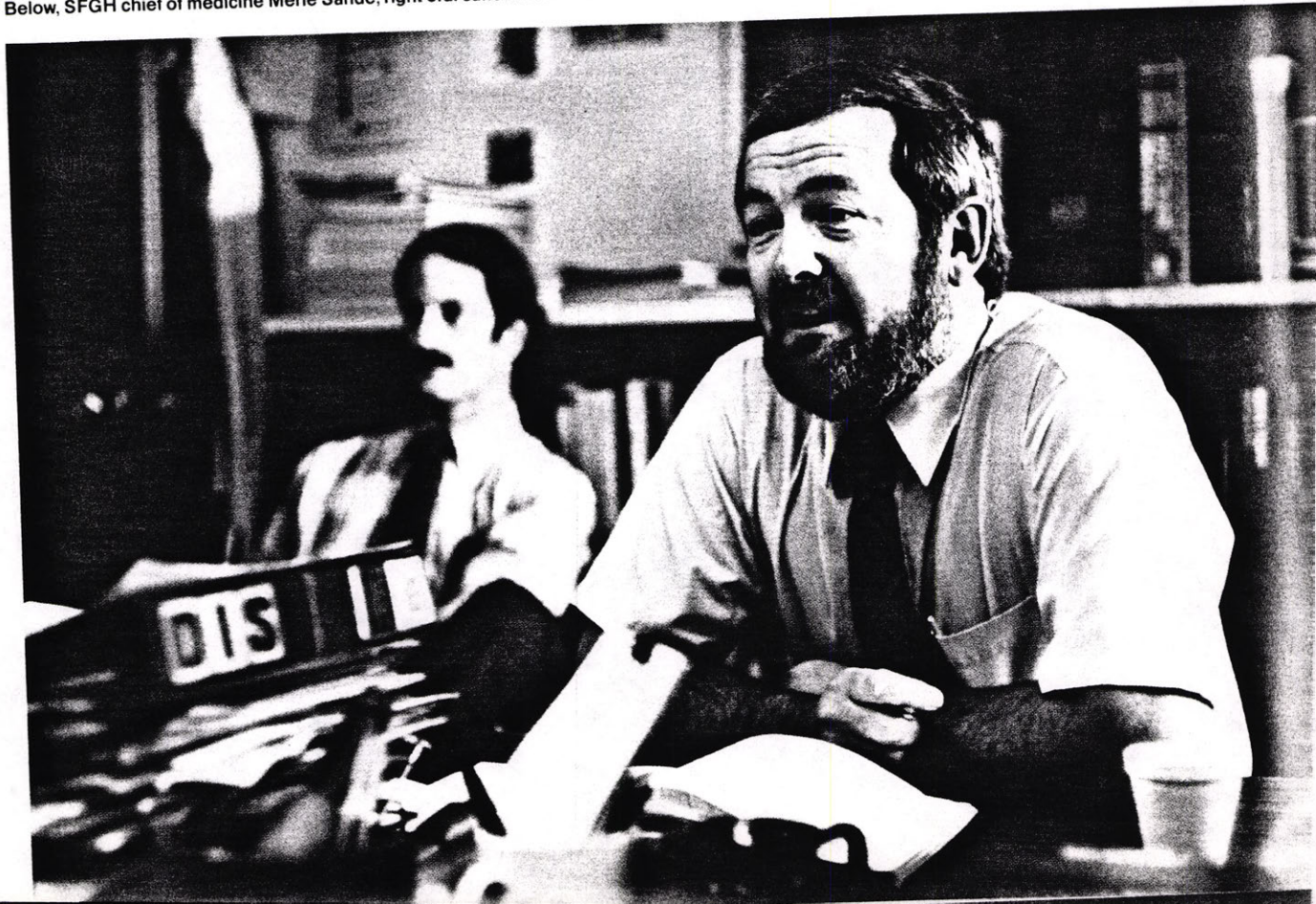
"AIDS continues to be a serious public health problem."

tal workers should take. A study at SFGH was started to evaluate risk factors for health care workers caring for AIDS patients.

Faculty from the Department of Psychiatry helped design an AIDS prevention project with funds from the S.F. Department of Public Health, aimed primarily at providing both information to at-risk youth and counseling services to AIDS-infected people.

Still, the nature of the disease and its long latency period guarantee that the number of AIDS patients will rise. And while one mystery—the cause of AIDS—apparently has been solved, many more remain. A vaccine is still probably years away, and AIDS continues to be a serious public health problem. Indeed, evidence indicates it is spreading to the heterosexual community. To judge by past performance, the UCSF response will continue to be immediate, concerned and resourceful.

Below, SFGH chief of medicine Merle Sande; right oral cancer AIDS researcher Francina Lozada doing skin test on AIDS patient.





Cell Sorters

by Jeff Miller

A little dye and a lot of laser make these machines the marvel of the labs

The machine looks something less than space-age sleek—two thin cylinders, about four feet long; an open frame faced with dials and switches; a computer keyboard topped by small monitoring screens; and a jumble of exposed cables.

What seems so unimposing on the outside, however, is a technological marvel at its core. For it is there that a liquid stream of cells the diameter of a human hair is forced through a vibrating nozzle, separated into tiny droplets, scrutinized by the light of one or two lasers, and sorted at the rate of 1,000 cells per second.

Such rapid analysis of cells and the ability to separate them into pure samples have made these \$300,000 machines, known as cell sorters, and similar ones, known as cell analyzers, key elements in research now going on at six different sites on the UCSF campus. The sites include Y.W. Kan's laboratory at the old UC Hospital building, the Immunogenetics and Transplant Laboratory, the Clinical Immunology Laboratory, Moffitt/Long Hospitals, the Brain Tumor Research Center and the off-campus laboratory at the Center for Educational Development (CED).

The UCSF effort has already led to advances in kidney transplantation. In time, it may also result in more effective treatment of certain cancers, as well as a better understanding of the immune system.

The principle behind cell sorting was first developed almost 20 years ago by Mack Fulwyler, now head of the Department of Laboratory Medicine's two-year-old Laboratory for Cell Analysis, located at CED on Folsom Street. Only recently, however, has the creation of more powerful sorting machines placed the technique on the cutting edge of medical research. The use of LCA instru-

ments is open to all clinicians and basic science researchers.

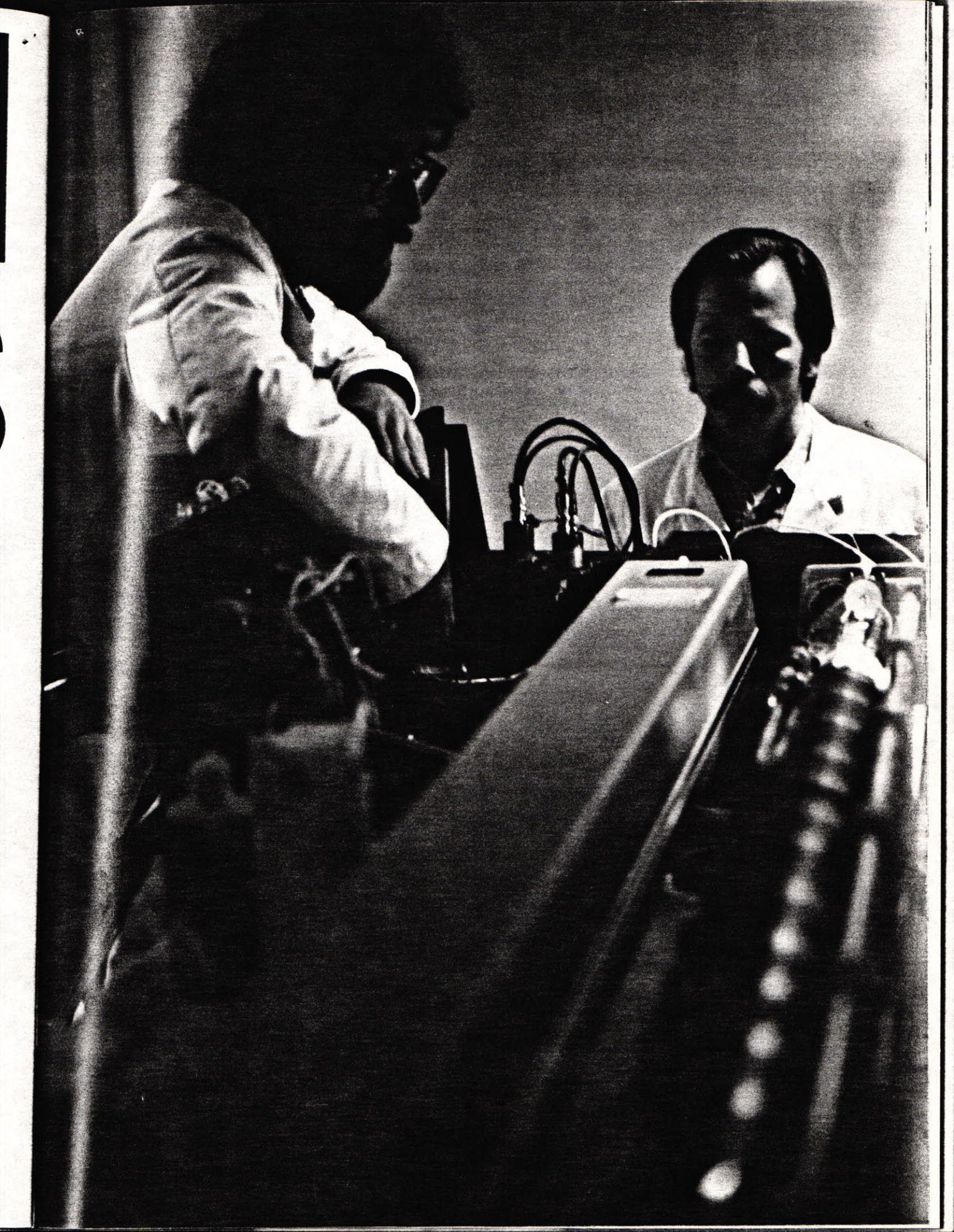
Howard Hughes medical investigators Y.W. Kan and Roger Lebo are using a customized dual laser sorter for their work in the analysis of chromosomes, the threadlike structures in a cell's nucleus that carry genes.

"We begin by disassociating chromosomes that have been separated from the rest of the cellular components," explains Lebo. "Then we stain them with fluorescent dyes, which bind only to DNA."

As the chromosomes are forced out of the nozzle and pass through the argon laser beams, the light activates the dye. This causes the individual chromosomes to flash—or fluoresce—differently, according to the amount of dye (DNA) they contain. The machine can be programmed to recognize these different flashes. And once the desired particles are identified, the operator can electrically charge and deflect the chromosome-containing droplets from the main stream onto special filter paper.

Using this basic technique, Lebo is able to separate very pure samples of most of the 23 human chromosome types. Filter-bound samples are then probed radioactively with isolated genes, which will bind only at that spot on a chromosome where their exact copy rests. Learning where an individual gene rests, or where one is missing or abnormal, is called genetic mapping.

"Of course, there are other ways of doing this," says Kan, "but they take much longer." Speed and accuracy already have helped Lebo locate the gene that is missing in the genetic muscle disorder known as McArdle's syndrome. Since then the procedure has been used to map numerous genes. "With development, this technique could be used clinically to screen patients for chromosome rear-



rangements associated with reproductive failure."

At the Immunogenetics and Transplant Laboratory, another dual laser machine is being used by lab director Marvin Garovoy and his colleagues to screen potential kidney recipients. The machine does this by analyzing the antibodies produced in the bloodstream of a kidney patient after the patient has received a blood transfusion from a potential donor.

"Before we got the machine three years ago, many donors were excluded and some patients not transplanted at all because we didn't have a sensitive way to distinguish between antibodies that were harmful and those that weren't. Now we do," says Garovoy.

Garovoy estimates that 100 kidney patients already have benefited from the new technology—either by receiving a kidney from a donor who would once have been excluded,

or by being spared a transplant that likely would have failed. The sorter has thus helped keep the one-year success rate for the donor-specific transfusion technique at 95 percent.

The transplant lab also is doing research in the area of bone marrow transplants where, all too often, the bone marrow is attacked by the recipient's immune system, causing what is known as graft vs. host disease.

Certain steps already can be taken to reduce the number of disease-causing cells in the bone marrow transplant mixture. But with the help of the cell sorter, UCSF researchers now have a more precise way of monitoring how successful those steps are *before* transplantation.

So far, the test results show a "marked decrease in graft vs. host disease," says Garovoy. The future may produce even more dramatic results, he adds. "There may come a time when we're using the sorter to remove harmful cells from bone marrow transplants while enriching them with others. In this way, we could actually replenish the patient's own immune system."

Reviewing the immune system is also the focus of a major research project in the Clinical Immunology Laboratory. The goal of the project is to shed light on the cellular events surrounding the collapse of the immune system in patients with Acquired Immune Deficiency Syndrome (AIDS). The researchers also hope to learn more about the relationship of this immune deficiency to viral infections and about the effects of therapy.

Because sorting of the various cells is not necessary in this research, Daniel Stites, director of the laboratory and professor of laboratory medicine, uses a machine called a cell analyzer to evaluate the cells' different properties.

Cell analyzers function on the same principle as the more costly sorters. But they are easier to operate and often use a mercury arc lamp instead of a laser to detect and measure fluorescence. They also represent a major advance over the traditional methods of microscope analysis while, at the same time, making some tests feasible that were not before.

One example is a routine clinical test now being performed in Stites' lab which determines the ratio of T-helper and T-suppressor cells (types of white blood cells that regulate the immune response) in patients suspected of having AIDS.

"We use the test to help physicians make their diagnosis," Stites remarks. "The test can't determine if a person has AIDS. But if the ratio between suppressor and helper cells is normal, that's strong evidence against it."

The analyzer also is being used to identify the type of cells involved in lymphomas and leukemias. "The therapy used in treating various kinds of leukemia is critically dependent on defining the cell type involved," Stites



Left, Laurence Marton, Fred Waldman and Mack Fulwyler at CED lab in program cosponsored by the Lawrence Livermore Laboratory and UCSF; opposite page, Marvin Garovoy in the Immunogenetics and Transplant Lab.

explains. "Only looking at cells under a microscope is no longer adequate in 1985. Cell analyzers are much more accurate. Using them also is less tedious."

Another analyzer, belonging to the Laboratory for Cell Analysis but located at Moffitt/Long Hospitals, is being used by Laurence Corash, chief of the hospital hematology service, to count reticulocytes. These immature red blood cells, which are released into the bloodstream during an emergency, offer a good index of red blood cell production and serve as a warning sign of blood disease. The instrument is also being used to identify antiplatelet antibodies in immune diseases.

The versatility of the cell sorter — which also can be used to analyze — has made it a valuable research tool at the UCSF Brain Tumor Research Center. There, Laurence Marton, chair of the Department of Laboratory Medicine, has been conducting experiments into the effectiveness of cancer drugs at various stages of a cancer cell's growth.

"Cells have minimum and maximum amounts of DNA depending on which of several phases of the cell cycle they're in," says Marton. "Using our single laser sorter to analyze for the DNA content of large numbers of cancer cells tells us how many cells are in each phase, something we couldn't easily distinguish otherwise."

This knowledge could make chemotherapy more successful, since some drugs are more effective than others at different cell cycle phases. "This kind of analysis could also help us design more potent cancer drugs that, at the same time, are not more toxic," Marton adds.

Cancer study also is part of the research objective of Fred Waldman, assistant professor in the same department, who is working jointly with UCSF's Cancer Research Institute. With the help of the single laser sorters at the CED laboratory, Waldman is analyzing and comparing cell growth in normal and malignant tissues.

"In the past, we had to measure aspects of cell growth with radioactivity. Because of the cell sorter, we can now measure the DNA synthetic activity more precisely and in much less time." Eventually, Waldman would like to be able to measure DNA synthesis in the bone marrow of normal and leukemic patients. These measurements might then help predict which patients would be more or less likely to respond to chemotherapy.

Although that seems a distant prospect now, the pace and scope of cell sorting and analyzing research at UCSF may help speed its arrival. Already, for example, seven different projects — ranging from the role of interferon in the immune defects associated with Down syndrome to the origin of oncogenes — are scheduled for the new dual laser sorter at Fulwyler's laboratory. Others are planned.

All of the projects seem likely to contribute to basic scientific knowledge. But they also are likely to help transform the very nature of the machines responsible for that contribution. As Waldman predicts, "What we're seeing now is the evolution of a purely research tool into a clinical one that should become increasingly important to the diagnosis and treatment of disease."



UCSF

*The
Science
of
Caring*

Nursing at University of California, San Francisco/1986

THE DEAN'S MESSAGE

After reading this second issue of *The Science of Caring*, you may wonder why we didn't call it *The Politics of Caring*. And, frankly, you would have a point. For certainly in the pages that follow, there is a great deal on the impact UCSF nurses are making on the nursing profession at home and around the world through their social, political and clinical activism.

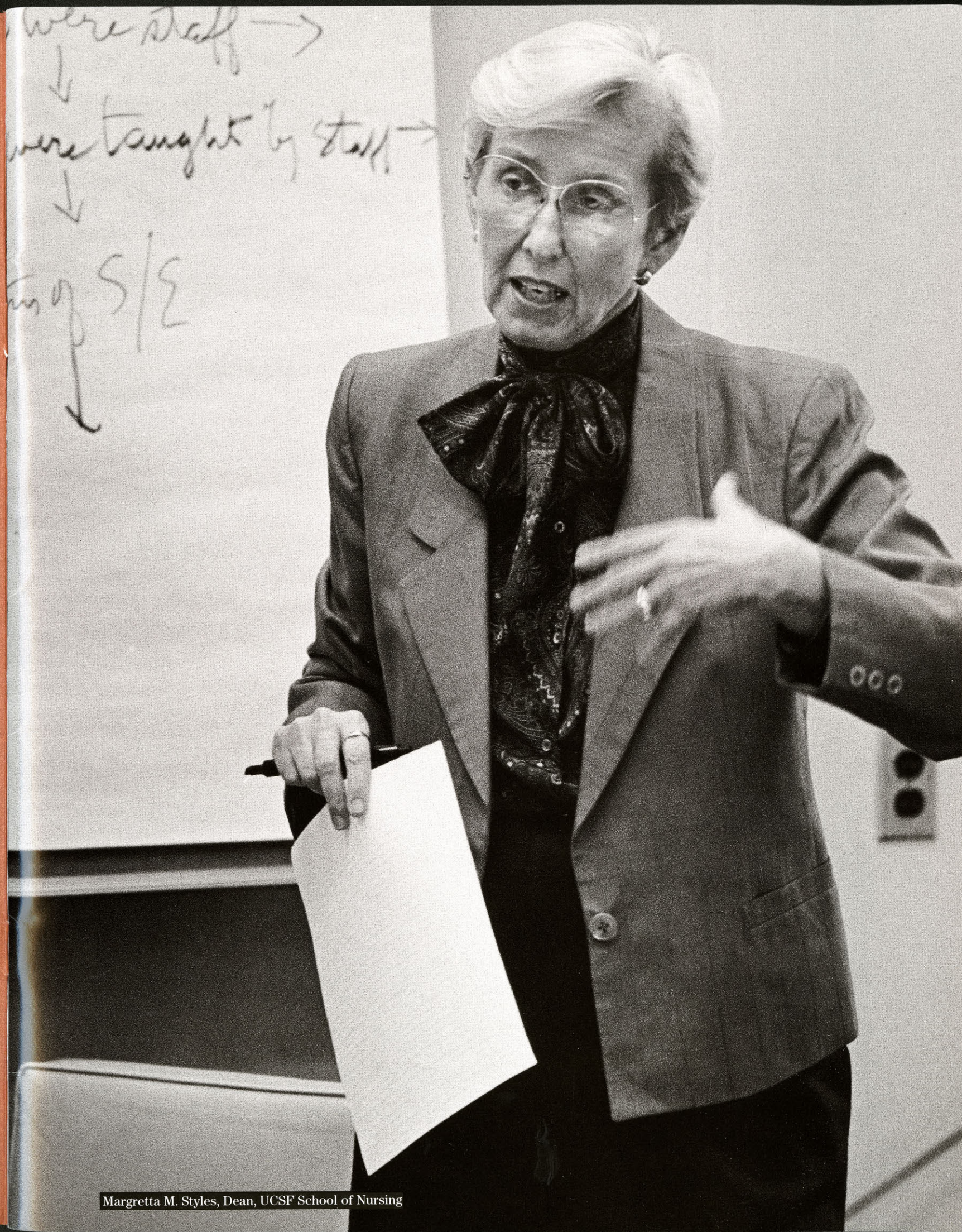
In the first issue of *The Science of Caring*, I mentioned that those in the nursing profession were fortunate to have the gift of being able to make a difference. And, in that first issue, we focused on the way research, service and education blended together in the form of scientific activism to improve nursing care.

Now—with nursing perched on a critical watershed where it can flow in one direction or another depending on our collective and individual acts—this issue is about activism of a different sort. These are examples of UCSF nurses at work in a variety of arenas. From state legislatures to Washington-based policy-action groups, from national professional associations to specialty societies, strides are being made . . . such as the development of improved social policy for the elderly, the evolution of nursing journals into more respected research publications, and the successful efforts of nurses to have some control over the regulations and legislation which affect nursing.

But, while the focus in this issue is to a great extent on political and social activism, the ultimate significance of the contributions made by the people in this magazine—and so many others from the UCSF campus—directly involves the future of nursing and its commitment to health care. And, what is our future if it is not bound directly to humanistic and scientific principles—the very same principles which led us originally to entitle our publication, *The Science of Caring*.

Margretta M. Styles

Margretta M. Styles
Dean, School of Nursing
University of California, San Francisco



Margretta M. Styles, Dean, UCSF School of Nursing



This bronze bust of Florence Nightingale—a gift of Constantine Raikes in 1983—stands at the entrance of the UCSF School of Nursing.

Nursing at the University of California, San Francisco, a health sciences campus, is many things.

It is, of course, the School of Nursing with its world-renowned faculty of educators and researchers and more than 500 postgraduate students pursuing master's and doctoral degrees in nursing science. Today, in fact, it is the only nursing school in the country to offer parallel DNS and PhD programs—the Doctor of Nursing Science (DNS) has been offered since 1965; the Doctor of Philosophy in Nursing (PhD) was instituted in 1984.

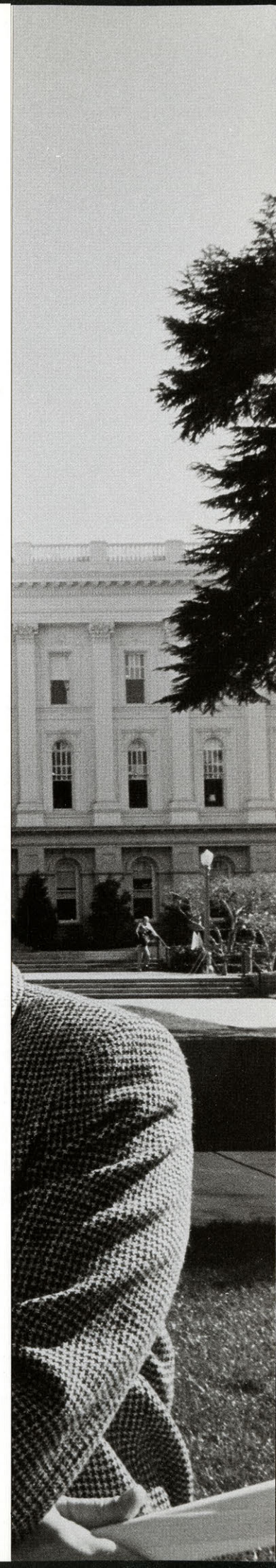
Nursing at UCSF is also more than 1000 nurses, nurse administrators, nurse practitioners, and clinical specialists who staff the Medical Center's acute care and psychiatric hospitals and ambulatory care services.

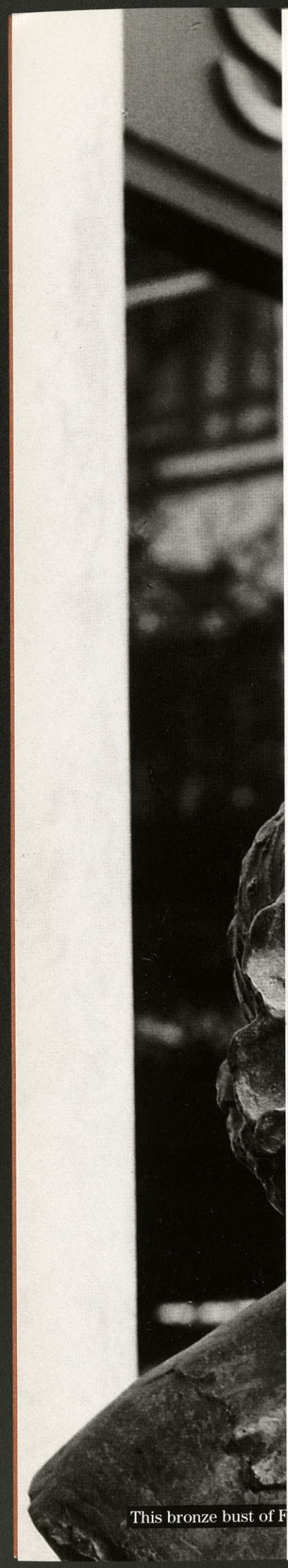
It is more than 200 non-salaried clinical faculty members who are not necessarily "on campus," but who volunteer a minimum of 60 hours a year teaching and serving as valuable resources and preceptors in specialties ranging from family nursing practice to nursing service administration.

Nursing at UCSF also means innovative programs designed to provide top-quality nursing care, not only in the hospitals and the clinics, but also in community settings where the lives of people at work and at home can be improved.

Moreover, it is the numerous graduates from the UCSF School of Nursing who have changed the face of nursing in this and faraway countries. And it's those who hold key positions throughout the state and the nation in patient care settings, administration, nursing school faculties and the government who have helped to advance the development of the nursing potential.

But above all else, nursing at UCSF is about the science of caring—the conviction that what sets the nursing profession apart from others is its ability to combine the discipline and knowledge of science with the intangible qualities involved in human care.





Fill a room with people in the so-called business of health care and all would agree that health care delivery as we know it today is undergoing massive structural change, from which it will emerge far different from its present state.

Because the various factors causing such an upheaval are so wide-ranging and complex, and since so much is at stake—namely, how our country will keep people well and care for the sick and the elderly—it is crucial that those involved in health care do their best to keep informed on the issues.

However, the issues are not necessarily the 'bedside' or 'patient care' matters in which nurses traditionally are educated or skilled. They now include talk of competition for the health care dollar, the profusion of medical conglomerates and corporate medicine, a push for more technology at a time when shorter hospitalizations are being mandated by tightened reimbursement programs, and the growth of vocal new 'consumers'—once known as patients!

In short, the traditional, service-oriented, charitable dimension of health care—with which nurses are quite at home—is being augmented by a retailing/marketing outlook—an expansionist viewpoint not easily embraced by all nurses.

Some of the changes nursing is faced with include an older clientele, a better informed and more participating public, expansion of settings for health care delivery, and modification of the numbers and kinds of nursing personnel needed in hospital-based care. More dramatic events, such as an overabundance of doctors, a highly educated citizenry and the opening of other desirable career choices for women, are important societal factors which may have an effect on nurses and nursing.

Though nurses may not be accustomed to taking active roles in turbulent "board room" discussions, taking part in legislative or governmental forums where decisions are made, or forming powerful coalitions with other interest groups, the time is long past when nurses can sit on the sidelines hoping for the best to happen.

Because of the strong leadership that many in the nursing profession have already exerted, opportunities do exist for nurses to become involved in the current controversies. In fact, more than ever before in the history of the nursing profession, nurses can influence health care delivery and develop roles that they want to play in its future.

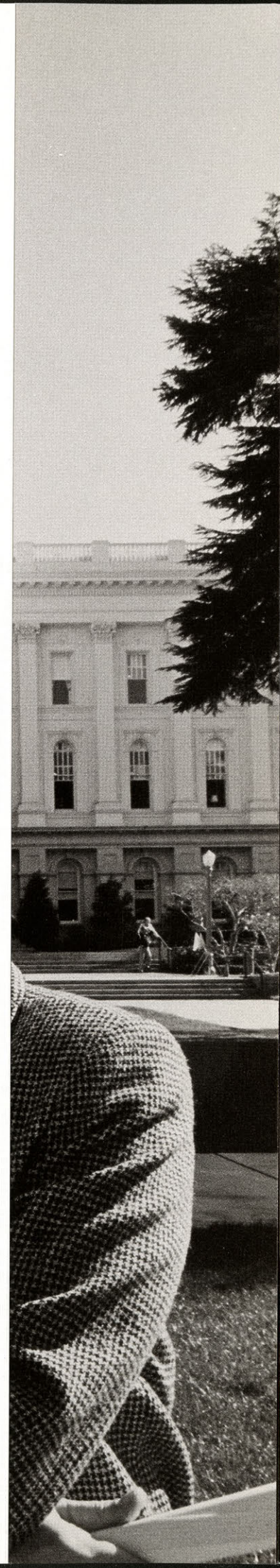
Says Pat Underwood, clinical professor at UCSF's School of Nursing and former president of the California Nurses Association: "Exciting opportunities await the nursing profession as the business of health

care makes its transition to a more competitive, market-driven industry. The changes now taking place should actually provide nurses with new avenues for personal and professional growth as they link quality and economy."

And, she adds: "We must become full-fledged partners in health care delivery systems. In fact, with the race on to cut expenses and shorten patient stays, we are now in a position of influence."

Because nurses are the most visible, available and continuous providers of care, they can serve as vital links between quality and cost. Their participation in patient education, disease prevention, discharge planning and basic health care assessment can go far in helping to bring down the cost of care and to ensure its high standards.

This issue of *The Science of Caring* offers a look at some of the ways in which nurses from the UCSF campus have made a difference in the direction of the nursing profession and the changing health care field. Through participation in local and national professional organizations and associations . . . through a reorganized and strengthened graduate degree program in administration aimed at preparing nurses for executive and management positions in health care . . . and through stimulating the clinical nurse specialist movement via a national symposium held for clinical nurse specialists—a role which, perhaps more than any other, represents the forward motion of nursing over the last two decades.

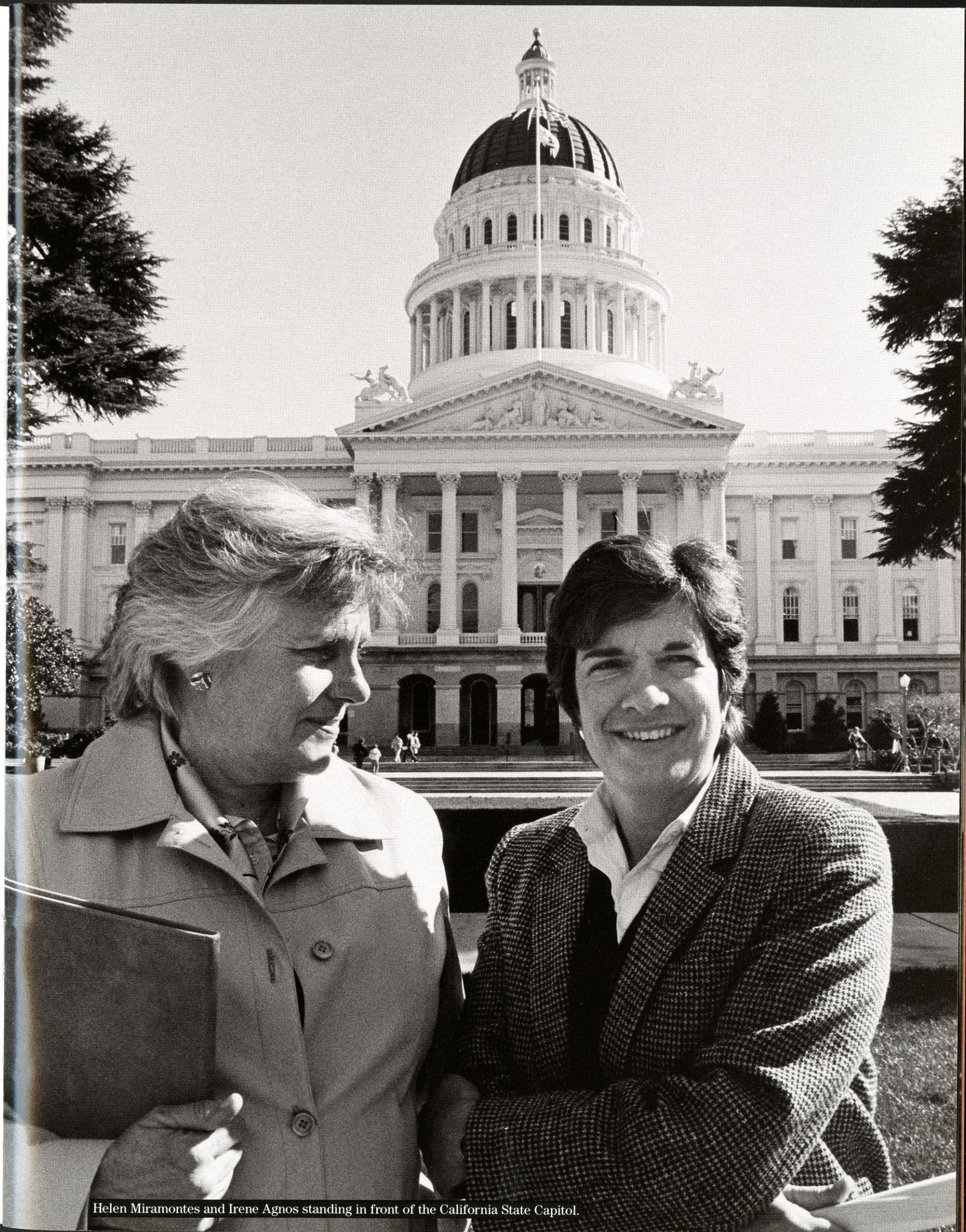


PARTICIPATION: ASSOCIATIONS, ORGANIZATIONS AND ADVOCACY

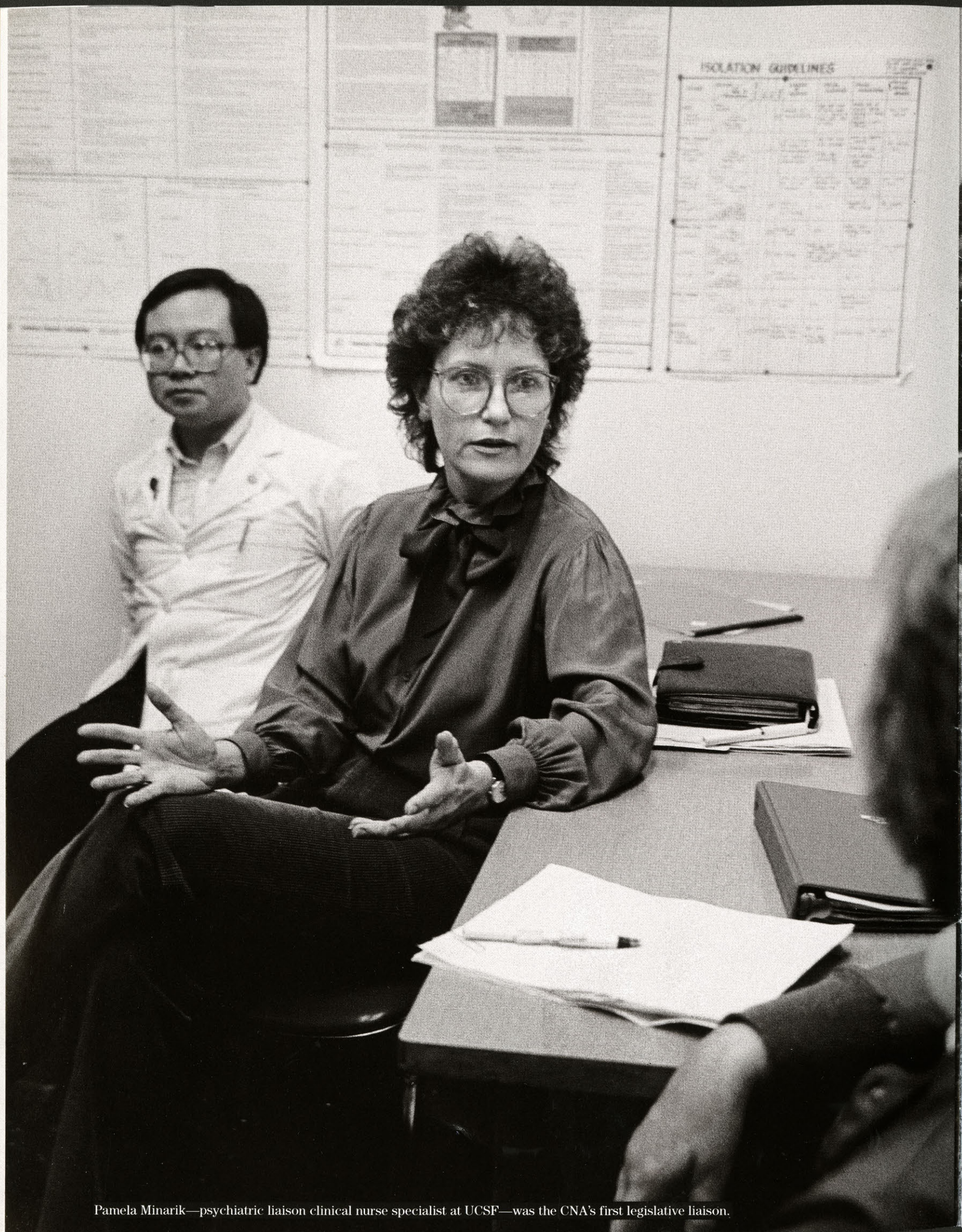
The state's only nursing lobby, the California Nurses Association, is one of the largest women's lobbies in Sacramento. With government—on all levels—playing an increasingly prominent role in the scope of nursing practice, CNA has, in recent years, made the creation of a strong governmental relations program one of its top priorities. Today, this program is succeeding because of the women who have committed themselves to it. Each of these women has a connection with the UCSF School of Nursing. CNA's immediate past president, Pat Underwood, is a member of the School's faculty and a 1978 alumna; Helen Miramontes, current CNA president, is a 1985 graduate of the School's master's degree program; Pamela Minarik, legislative liaison and active in the CNA government relations program, is a non-salaried clinical faculty member of the School and a 1981 graduate of its master's degree program. She is also a clinical nurse specialist at UCSF's Moffitt-Long Hospitals. Another member of the School's non-salaried clinical faculty is Irene Agnos, director of CNA's government relations.

Times have certainly changed since three years ago when Pat Underwood—newly-elected president of the California Nurses Association at the time—and Irene Agnos—CNA's first nurse director of government relations—kept an appointment in Sacramento with a key California assemblyman to discuss a piece of legislation about which CNA had strong opinions.

Cooling their heels in the assemblyman's office for more than three hours beyond their appointed time, they watched incredulously as others marched in—seemingly without appointments. When they were finally ushered in, they received perfunctory greetings from the assemblyman, who then turned them over to one of his aides. The meeting was brief—and interrupted by several phone calls.



Helen Miramontes and Irene Agnos standing in front of the California State Capitol.



Pamela Minarik—psychiatric liaison clinical nurse specialist at UCSF—was the CNA's first legislative liaison.

Today, Underwood, Agnos and the current CNA president, Helen Miramontes, are treated differently. Appointments are punctually made and kept, often at the initiation of legislators who ask for and rely upon CNA's input on health care matters. At major Capitol functions—to which, not long ago, CNA would either not have been invited or, at best, been assigned a table in the rear of the room behind a column—CNA guests are frequently found seated on the podium alongside other major associations interested in public policy development.

What happened in three years to make such a big difference?

Says Underwood, whose three-year term of office ended last September: "The CNA had to decide whether it was going to be a nursing society and put on teas or be a professional organization and get involved in health care policy-making.

"Because there was no other way to make an impact in the 1960s and 1970s, the CNA had already committed itself to collective bargaining issues," Underwood continues. "Clearly, now in the 80s, the way for us to make an impact is in active participation in institutional and state governance. If not, we stand to lose all the ground we have gained in the past."

Recognizing that there was increasing competition for political office and campaign contributions, Underwood and the CNA staff turned its efforts to developing a healthy, sizeable Political Action Committee or PAC.

Continues Underwood: "We had to accept a cruel reality. If we want politicians in office who are sensitive to nursing issues, we have to elect them. And to elect them, we need votes . . . and money."

Adds Agnos: "We'd like to make politics different but, until the rules change, we'll play the game the way everybody else does. With power, campaign contributions and influencing politicians."

In addition to strengthening its PAC—now the largest controlled by women in California—CNA has undertaken an extensive statewide educational effort to keep its members informed and involved in legislative matters. As a non-salaried clinical faculty member of the UCSF School of Nursing, Agnos teaches a course in legislative processes which has been a major course in the nursing administration program. Part of the course is a slide presentation developed by staff at CNA in which the passage of a bill into law in Sacramento is likened to a complicated long-distance race consisting of a number of hurdles.

The moderator reminds the students: "In the Capitol arena being right isn't always enough. You have to learn how to win rights. Plus," she adds, "it's a crowded track with many interests vying for attention in California's legislative halls."





"Nurses," says Underwood, "should be asking themselves some tough questions these days . . . like, where will I be practicing in five years or in ten years. Where will we all fit under the new 'corporate' medicine. Maybe *we* should be packaging ourselves and selling our services directly to these new conglomerates as the physicians are beginning to do."

A key program undertaken by CNA in recent years is the legislative liaison program. Pamela Minarik, UCSF psychiatric liaison clinical nurse specialist, was the first person to participate in the program.

She recalls, "When I left my employment to travel for a year back in 1974, the Nursing Practice Act had just been revised, and I was enthusiastic about the seemingly endless possibilities of growth for the nursing profession.

"But when I returned, I was amazed. Nothing much had happened. Most nurses were still unaware of the opportunities which the Act had created for them. So I decided then and there to become active and joined the local region of the CNA on its government relations committee. One of the first things I had to do was re-learn basic civics about how bills get drafted and passed into law."

Later, Minarik began to contact her State assemblyman, who happened to share many of CNA's viewpoints. Over the years, a strong relationship of mutual support and information-sharing has developed between the assemblyman, members of his staff, and Minarik. In fact, the development and nurturing of such productive, positive relationships with legislators is an important role for each CNA legislative liaison, who both inform representatives and staff about CNA's point of view on issues and offer pertinent background, speakers or resources, and also gather information from legislators on issues which CNA wants to monitor.

"With all the health-care bills being heard these days," adds Minarik, "lawmakers—especially if they don't have any background in health care—need and actually seek out knowledgeable people."

One way of showing the increased interest in law-making among nurses is the attendance at CNA's annual Nursing Day held in Sacramento. What was once a somewhat small event has grown to attract over 400 nurses. During the day, they meet key legislators, take courses in the legislative process, and get briefed on current key issues.

"Even though it is gratifying to see the interest spreading," says Underwood, "nurses need to wake up to the fact that the scope of practice for nursing is still being determined by others. It's up to us to stay informed and active on the issues, because it is clear that the ones who are most informed and well-organized are going to have their issues addressed."

Carroll Estes hopes to have a direct impact on public policy which affects our country's growing elderly population, through her work with such groups as the California-based American Society on Aging (ASA)—formerly the Western Gerontological Society—and the Washington, DC-based Association for Gerontology in Higher Education (AGHE).

"Many of the issues we're dealing with in the 1980s," says Estes, who is director of the campus research unit Institute for Health and Aging, and chair of the School's Department of Social and Behavioral Sciences, "are vital to the health and well-being of our elderly people.

"And, even though there are, in fact, more older people today who are better off financially than in years past, more than five million older Americans still live in poverty and have inadequate access to health care. Particularly worrisome is the growing gap between the comfortable elderly and the poor elderly—especially since the brunt of recent federal cutbacks is being felt by the poor elderly."

Since 1974, Estes has been a frequent consultant to the US Senate's Special Committee on Aging and the US House of Representatives' Select Committee on Aging. For many years, she has served as consultant to the National Administration on Aging.

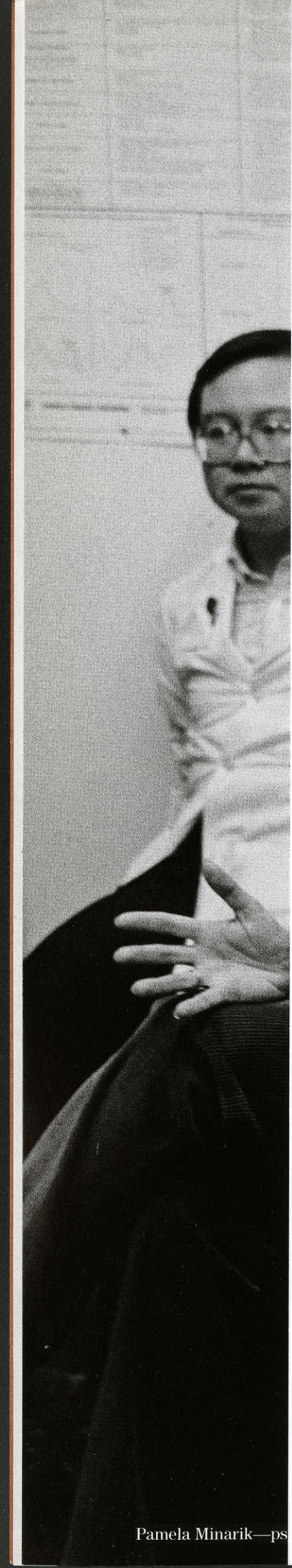
As a member of the prestigious Institute of Medicine since 1982, Estes has seen a growing number of nurses admitted to that group, which has helped put the issues of interest to the nursing profession—including aging and geriatric issues—on the agenda of this highly regarded policy-making institution.

A widely-published author in the field of gerontology, Estes says, "The future of our country's aging policy for low-income elderly individuals is more uncertain now than at any time in 50 years. Plus, the current attempt to link the problems of the economy with the issue of aging is one of the most potentially serious threats to a viable public policy for the elderly that we have seen in many years."

Last winter, Estes and Dorothy Rice, professor in residence, published a paper in the well-known national journal *Health Affairs*. The paper, "Health of the Elderly: Policy Issues and Challenges," reflected research sponsored by the Commonwealth Fund, the National Center for Health Sciences Research and the Pew Memorial Trust.

Rice, formerly director of the National Center for Health Statistics, joined the School of Nursing's faculty in 1982. She is internationally recognized as the key analyst of the national health expenditure. Her





updated "Estimating the Cost of Illness" has recently been published in the *Health Care Financing Review*.

In their study, Rice and Estes propose an agenda "that will require action at the community, state and national levels in order to develop and establish a long-term care policy which meets the multiple needs of the increasing number of elderly and encourages healthy aging, independence and autonomy in our old age."

As president of ASA from 1982 through 1984 and as president of AGHE from 1981 through 1983, Estes has been in a particularly visible position to voice these concerns at local, state and national levels.

While the work of AGHE has been directed at all aspects of education in an aging society, it has committed itself to promoting gerontological and geriatric education in nursing. The awareness of the importance of geriatric health care issues by AGHE is in large part due to Estes' involvement with the group.

Not a nurse herself, she says, "It may seem perfectly obvious that since nurses are the principal care-givers in health care settings, they should play prominent roles in groups such as AGHE. But this hasn't been the case."

Now, however, nursing does play an active part in this group of prestigious academicians. In fact, AGHE's 1983 mid-year conference—held in San Francisco—addressed issues in geriatric nursing education and clinical practice, with several speakers selected from the UCSF School of Nursing's faculty, including Charlene Harrington, Laura Reif, Pat Underwood and Estes.

Although no longer president of ASA, Estes remains active as a member of that organization's executive committee and is current co-chair of the Association's Public Policy Committee. ASA is one of the largest national organizations devoted to the concerns of the aging population. Its annual meetings attract thousands of participants and help to keep the issues of the elderly in the public eye. The major priorities and concerns of its members currently include long-term care, the impact of medical cost containment and the needs of the elderly.

In a further effort to raise public consciousness to the problems facing the elderly, ASA held its first Summer Series on Aging last summer on the UCSF campus. The conference was co-sponsored by the School of Nursing through its Institute for Health and Aging and was attended by more than 250 people.

"Groups like ASA," says Estes, "rely on the work of researchers such as myself and others here at UCSF to help keep their membership informed on where policies are failing and what action should be taken."



Carroll Estes reviews data on the health status of the nation with Dorothy Rice.



Daily activism on the part of UCSF nurses extends to clinical care of the aged population.

Through groups like ASA, we are frequently invited to testify and share our research with those who make policy—both in Washington and state capitols throughout the country.”

ASA has alerted its members recently to the disturbing effects of Medicare cost-cutting on services for the elderly. These concerns were raised as a result of a School of Nursing research project of Estes, Philip Lee and Juanita Wood, whose findings were published in the *Journal of Public Health Policy* and *Social Science and Medicine*.

“We discovered,” says Estes, “that the DRG system of payment—which basically limits hospital stays for Medicare payments on the basis of diagnosis upon admission—is placing a heavy acute-care burden on social services which were originally designed to serve the ambulatory chronically ill and the well elderly.

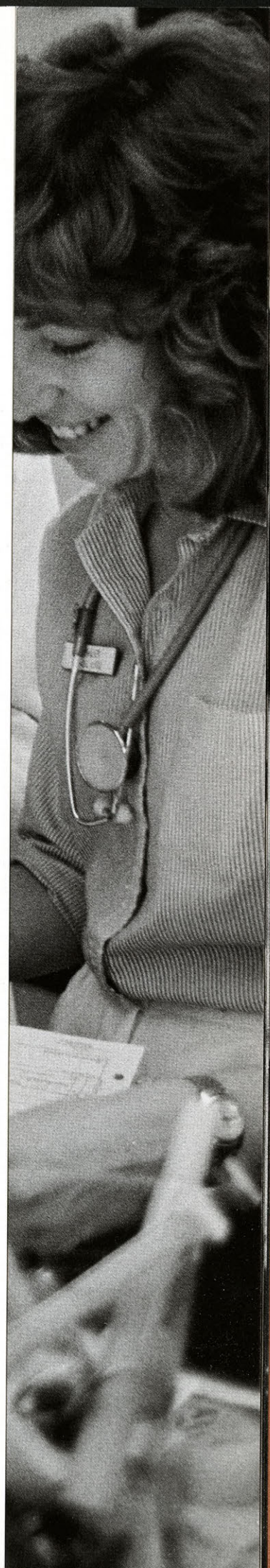
“Since 1982,” she continues, “more than 25 percent of the federal funding has been cut from social services for the elderly. The network of social support systems—established so carefully in the 1970s—is being profoundly changed. As a result, these services are now being targeted to the frail elderly eligible for limited Medicare benefits, or those who can afford to pay—leaving many others out in the cold.

“Services such as adult day health care, home health, homemaker services and senior centers—which were once considered alternatives to institutionalization—are being adapted to fit the acute-care bias of Medicare payments, in order to qualify for reimbursement or payment.”

Estes emphasizes: “What we need to do is free ourselves from the acute-care model of Medicare. Wellness requires a continuum of care which is available as needed to meet different needs at different times. Social support networks and social services are preventive medicine. What sense does it make to deprive people of vital supports unless or until they become acutely ill?”

Because of the interest generated in part by this research project and UCSF’s publicity of the study, the chairman of the Senate Special Committee on Aging has decided to hold nationwide hearings on the impact of DRGs on community services and the elderly.

Noting that ASA’s Public Policy Committee has activated its 5000 members to urge Congress to restore funding to social service programs for the aging, Estes says, “Activists from all over the country will be there at the hearings to testify. And while it will be an uphill battle, they’re starting early and aim to win.”





Helen Ripple puts it succinctly—"We nurses treat patients. That's our job.

"But, frankly," she adds, "having to cope with the incredibly complex changes in patient care caused by the new reimbursement program makes it harder and harder for us to do that job well."

One of those on the UCSF campus who is most active in outside professional organizations, Ripple, associate director of UCSF Medical Center and associate dean of the School of Nursing, has played a prominent role in recent years in several national nursing professional organizations. Most recently she has served as president of the Chicago-based American Organization of Nurse Executives, (AONE), formerly known as the American Society for Nursing Service Administrators. AONE is a division of the American Hospital Association.

Under Ripple, there grew a new vision of where AONE should be going.

"Coming to terms with who we were and what we wanted to be as an association led us to change our name," says Ripple. "But it was more than just a name change. Now, as an organization, AONE has moved more centrally into the American Hospital Association and, consequently, into a more powerful position within the Association."

During her presidency, AONE developed a close collaboration with the National League for Nursing, the American Association of Colleges of Nursing and the American Nurses Association.

"Achieving this collaboration," says Ripple, "took time, but it is worth it. Now, as a coalition we can achieve much more than when we acted as single organizations."

As a national organization, AONE takes strong—and vocal—positions on health care and professional legislation. With its own Washington-based lobbyist, it keeps its members thoroughly briefed on issues ranging from private health insurers, Medicare regulations, nursing practice acts, DRGs and nursing care.

One of Ripple's own favorite issues these days concerns the importance of increased funding for graduate nursing education.

"We don't have enough nurses who are either master's or doctorally prepared," she says. "And education is clearly the key to our future. Moreover, with nurses now such an integral part of most executive management teams—at least in most inpatient settings—it is particularly important that we see to it that the business and management skills of nurse administrators are taught at the graduate level."

Ripple points out that AONE has, as an organization, interfaced with other educational and administrative councils to assure that the skills of nurse-administrators are the best possible.

"This is crucial if we are to step off of the sidelines and get involved in the important issues of today," says Ripple.

"We nurses have to grapple with tough questions. Fiscal issues, cost effectiveness of care and administrative budgeting. And in dealing with these issues, we have to commit ourselves to the importance of undertaking more research to support our position.

"Meanwhile, of course," she adds, "we have to continue doing good things with our profession so that we keep people interested in becoming nurses."

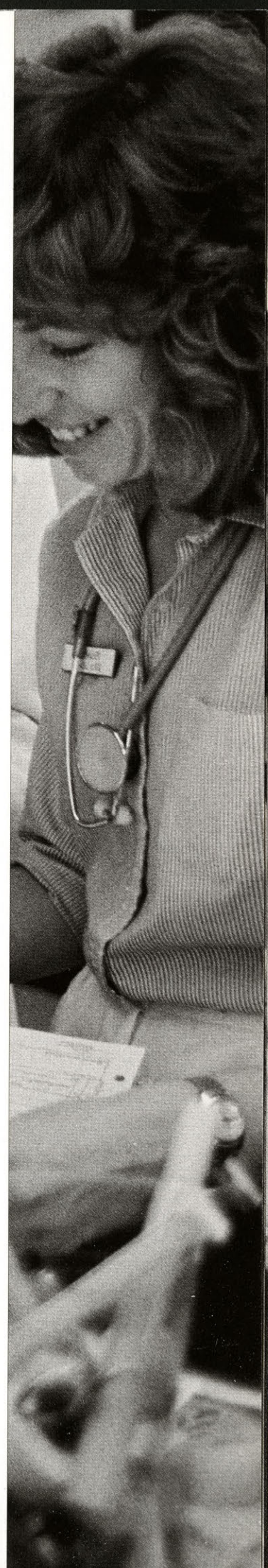
Many nurses from the UCSF campus have contributed to the development of nursing throughout the world—either in research, teaching or clinical matters. However, in the last decade, Dean Margretta Styles has, more than anyone else, brought international recognition and visibility to the School of Nursing. In 1985 the School was co-sponsor of two conferences, both prior to and following the International Council of Nurses Quadrennial Congress held in Tel Aviv. The pre-ICN conference sponsored by this School and the School of Nursing at Tel Aviv University, brought together experts from around the world in research on social support. The follow-up conference was second in a series designed to develop an international network of nursing schools aimed at evaluating issues of mutual concern and interest to all involved in graduate nursing education.

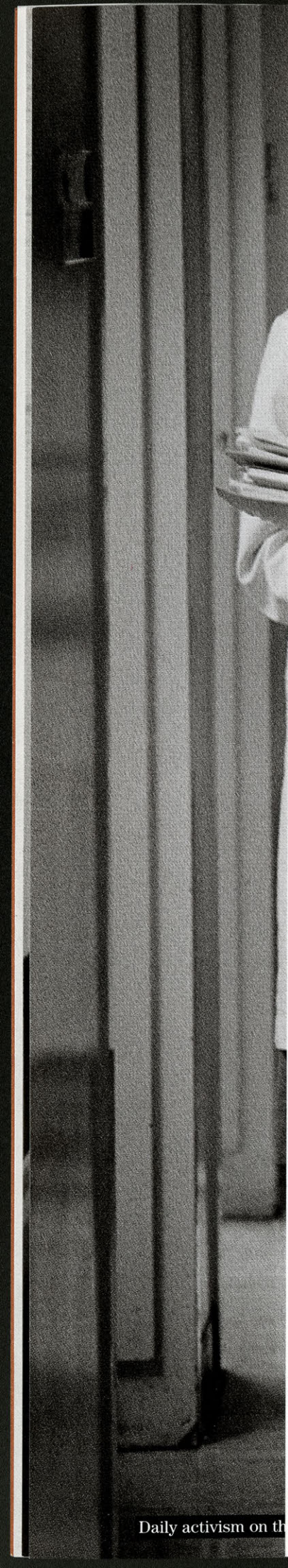
When Dean Styles presented the results of her year-long, world-wide review of nursing regulation at ICN's 1985 Quadrennial Congress in Tel Aviv last June, she threw out a challenge to her audience.

"Think of a world," she said, "in which nursing is at the forefront of health care . . . a world in which nurses are a strong, vital and dynamic social force . . . a world in which the Director General of the World Health Organization is a nurse."

Serving as director of the ICN project on Nursing Regulation, Styles concluded that regulation—in all its many aspects—can play a major role in shaping such a world.

"Regulation," she said, "can significantly strengthen or weaken our future."





Styles' definition of regulation throughout the study was "the forms and processes whereby order, consistency and control are brought to an occupation and its practice."

The study—largely completed during Dean Styles' sabbatical in 1984—required dealing with myriad governments, economic and educational systems, traditions, cultures and various stages of development in the area of regulation.

Undertaken to assist the ICN in developing an official position on the regulation of nursing, the study was used later in the year by the World Health Organization Study Group in its discussions relating to primary health care. It has led to simultaneous position statements promulgated by ICN and WHO for use as a worldwide guideline for professional regulation.

"Although greater progress has been made in some regions and on some matters than others," Styles concluded, "it is clear that nursing is in transition to a full professional status."

One surprising conclusion from the study was that nursing has no universal meaning and, also significantly, that the word "nurse" apparently has no singular meaning within many countries.

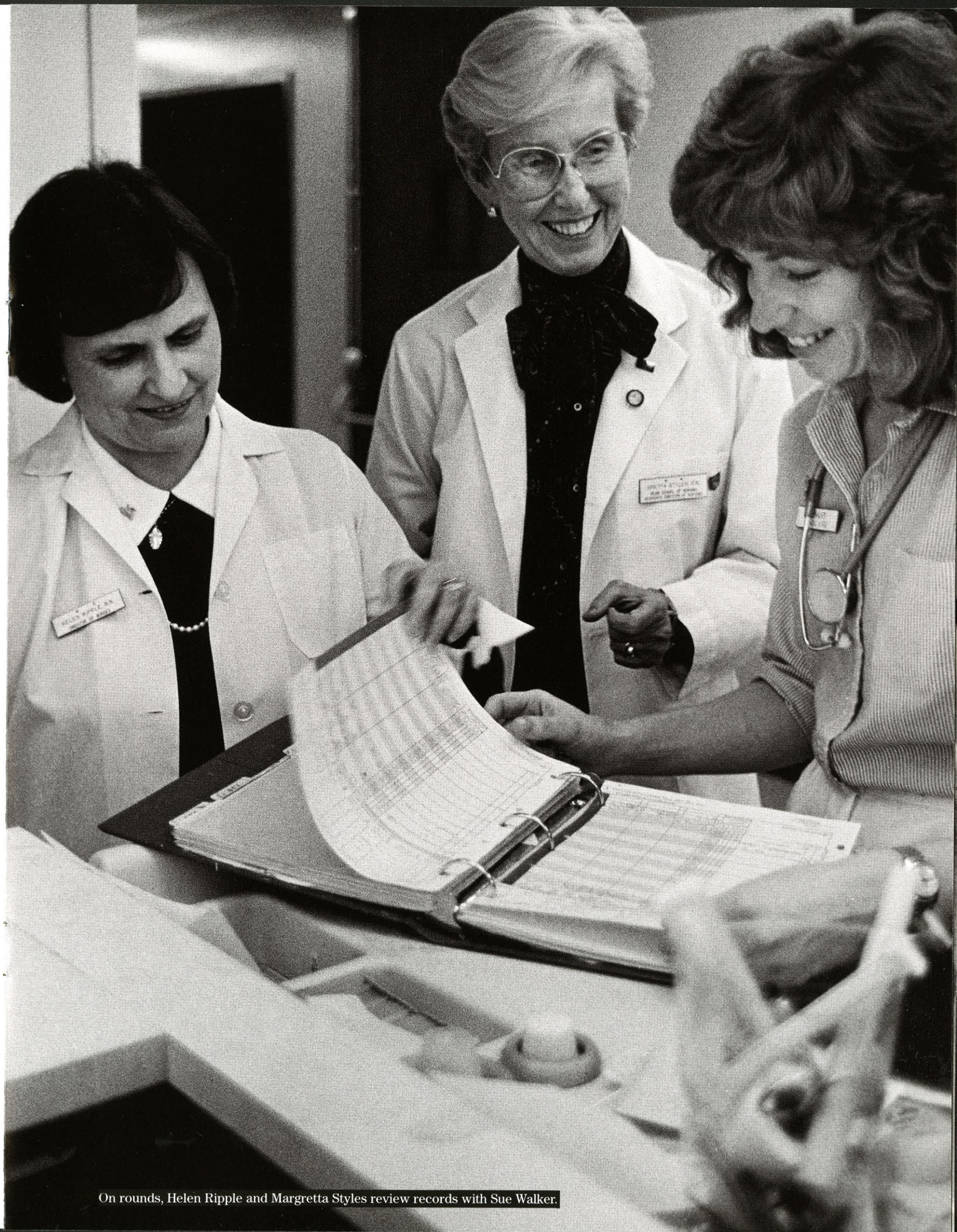
Regarding the policy objectives for nursing regulation, Styles said: "The central purpose of statutory regulation for nursing should be to protect the public, ensuring competent, accessible nursing care."

The regulatory system itself should include features to ensure that practitioners maintain knowledge and practice skills in accord with current health needs and the current state of the art in nursing.

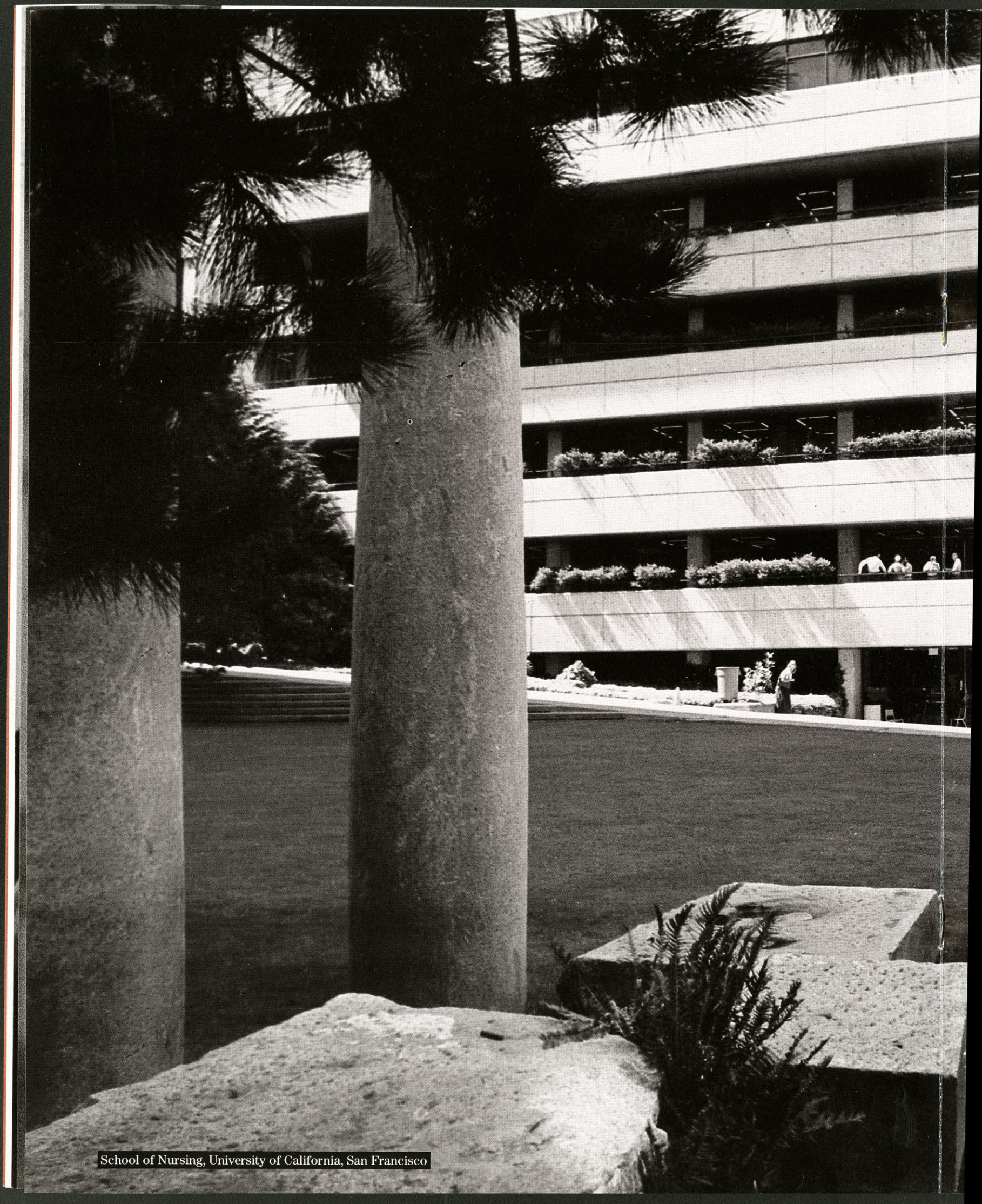
Styles concluded that if all the recommendations of the study were put into practice, emphasis would shift from the government to the profession as the agent of regulation. Additionally, the directions outlined would, she says, clarify the structure, accountability and scope of practice of the profession; provide parity for nursing with professions in standards of education and autonomy of practice; and prepare nurses for their appropriate role in primary health care and health policy.

Early this year, Dean Styles announced her decision to step down as dean, effective January 2, 1987—her tenth anniversary in the position.

In making the announcement, she said, "I'm looking forward to re-joining the faculty here on a full-time basis after a short administrative leave. I'm also very excited about the possibility of serving as the first occupant of the newly established James P. and Marjorie A. Livingston Chair in Nursing." The Chair—named for Mr. Livingston, retired president and CEO of National Medical Enterprises, Inc., and his wife—was established in honor of nursing service directors who have helped Mr. Livingston over the years in his endeavors in the health care services field.



On rounds, Helen Ripple and Margretta Styles review records with Sue Walker.



School of Nursing, University of California, San Francisco





Katharyn May helped turn *JOGNN* into a journal offering more research-oriented articles.

One of Katharyn May's fondest memories as a member of the editorial board of *JOGNN*—the official publication of The Nurses Association of The American College of Obstetricians and Gynecologists (ACOG)—was the time not long ago when the board made a unanimous decision to print an article written by a nurse practitioner which disputed a major drug company's own product research concerning one of its drugs.

"The company was a major advertiser and exhibitor at ACOG conventions and put a tremendous amount of pressure on us—including threat of a lawsuit—to suppress the article," says May, who is an associate professor in the School of Nursing's Family Health Care Nursing Department.

After evaluating the article, however, the board was totally satisfied that the nurse-author had her facts straight and recommended printing it.

There are a couple of things in particular about this incident that please May.

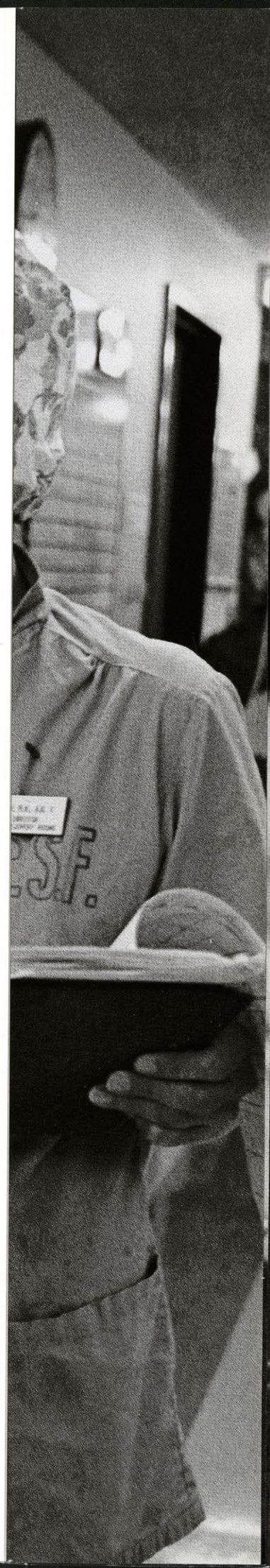
"First," she says, "we had a nurse who really knew her facts, had thoroughly familiarized herself with all the pertinent literature on the subject and was prepared to back her statements. And, second, as an editorial board comprised of six nurse-scientists and four clinical nurses, we pulled together and took a unanimous stand. I honestly don't think this would have occurred five or six years ago. The article would not have been published, either because we would not have had enough confidence in this nurse-author's interpretation in the first place, or because we would have tried to avoid the risks of publishing the article."

The case also reflects an interesting trend that has occurred at *JOGNN* and a few other nursing journals in recent years . . . and that is the metamorphosis into a publication whose readers—mostly nurses—expect and get well-researched articles, with carefully thought-out conclusions, and backed up with hard data.

"For far too long," says May, "nurses have written and read 'nice' articles. You know, the sort of thing that feeds the soap opera image of nurses. Traditionally, there has been very little published in clinically-focused nursing journals with any real data or dependence on research."

Soon after she was appointed to the editorial board in 1980, May became frustrated with the caliber of the articles she was being asked to review for publication.

"For example," she recalls, "there were a lot of articles in those days dealing with birth and bonding, which had become a very popular, trendy





concept during the 1970s. It was believed that there was a 'sensitive period' of 14 to 16 minutes during which a baby should bond with one or both of his parents—either that or end up a pitiable creature living an unhappy life. This had become a widely accepted proviso by professionals and the public as part of a good birthing experience.

While May agrees that bonding may be nice, she says, "The problem is that there isn't one shred of research which supports the idea that parents who don't get contact with their newborn after birth can't go on to develop a close relationship with their baby."

In spite of this, May and her colleagues on the editorial board were reviewing paper after paper submitted for publication incorporating this overly-simplified idea about bonding.

"Since the members of the board are spread out all over the country," says May, "we keep in touch over the phone. It turned out as we called each other that we were all feeling similarly frustrated at the lack of substance or documentation in the articles."

"We decided to take a hard tack and began rejecting papers, sending them back with critical comments which questioned the logic or research base for the conclusions."

Happily, the tactic worked.

"We began seeing papers of an entirely different nature. I think we were able to successfully straddle the gap between what was being said about clinical practice and what the related research actually said. In the process, we turned *JOGNN* into a much more reputable journal."

And, while the change has been subtle, May thinks it indicates the contributions which nurse-scientists such as herself can make toward the continued growth of the nursing profession.

"Nurses must become better consumers of research," she says, "if we are to keep up with what's going on in the health care world. I believe very strongly that research is—and must be—a legitimate part of our clinical practice. And, I hope in the future we'll see professional nursing organizations not only encouraging this trend, but also willing to take a stand on the importance of closing the gap between research and nursing practice."

As newly-elected treasurer of the Association of Operating Room Nurses (AORN), Linda Groah, UCSF's director of nursing, operating and recovery rooms and clinical instructor in physiological nursing at the School of Nursing, has a strong appreciation for the theme of this year's 33rd AORN Congress—"Unity: Pathway to Power."

"At times like these," Groah says, "when no one really knows what's going to happen to the nursing profession, it's important—if we're going to control the destiny of our practice—that we work together as much as possible, no matter how diverse our practices and specialties are."

"At our convention in March, 1986," continues Groah, "we looked at new ways to increase the professionalism of perioperative nurses and explored possibilities which could best influence the inherent power of nursing to accomplish our goals for health care. Plus we examined possible strategies for building a professional cohesiveness aimed at improving quality nursing practice in operating rooms."

Pointing out that nurses are beginning to wake up to their ability to influence policy-makers—both individually in the voting booth and collectively in the halls of the legislature—Groah says: "Not so long ago, you would never see an editorial exhorting nurses 'not to abdicate your responsibility in the legislative arena,' yet that's exactly what the president of AORN did recently in our monthly publication. She strongly admonished AORN's 33,000 members that all nurses need to be 'informed and become involved in legislative matters that affect patients' access to medical care and our own practice.'"

One of the issues which AORN—one of nursing's largest specialty associations—has met head-on was the new requirements from the Joint Commission on Accreditation of Hospitals (JCAH) regarding credentialing for non-physician health care providers beginning in 1986.

"Our Nursing Practice Committee," Groah explains, "has developed a model for credentialing to comply with these new standards and, I think, we're the first nursing specialty to have developed such a model."

Another issue closely monitored by AORN for its members was a proposed change in the Medicare regulations by the Department of Health and Human Services, which recommended that surgical technicians be allowed to circulate in the operating room.

"This is *clearly* something we felt was a deterrent to good patient care," says Groah, "and we couldn't just sit back and not do anything about it. Surgical technicians do not have the preparation for making





some of the decisions which have to be made during surgery—especially with some of the complicated procedures on acutely-ill patients being performed nowadays.”

Spearheaded by AORN, a massive letter-writing campaign was undertaken prior to publication of the new regulations in January 1983. Groah says, “Carolyn Davis, who was director of HHS’s Health Care Financing Administration at the time, told me that this was the single biggest response to proposed changes in Medicare regs that HHS ever received!”

The campaign proved successful. The new Medicare regulations specified that hospitals which accept Medicare funds must hire registered nurses to perform circulating duties.

Groah believes that through organizations such as AORN nurses can be better informed about current issues and better prepared to protect the profession’s future.

“For example,” she says, “we’re aware of a recent survey of CEOs across the country which indicates that in 1986 they expect higher productivity from operating rooms because of the demands of the new prospective payment programs. To do this, they’re going to be looking at staffing issues, such as the ratio of nurses to technicians. And it’ll be up to us—especially administrators—to demonstrate and articulate the necessity of maintaining quality care in the OR. We must demonstrate how nursing makes the difference in patient care.”

Of her work with AORN, Groah says, “I think it’s important that nursing leadership here be allowed to be active in this way, thus becoming involved and sensitive to issues at the national level. The actual benefits, however, of such participation and activism are significant in ways which can’t be costed out. For example, it can make recruitment and retention of staff nurses easier because nurses like being associated with prestigious departments and also appreciate the opportunity to learn about what’s going on beyond the institution.”



Linda Groah (right) reviewing the surgery schedule with Rosemary Welde.



Marilyn Flood leading a class for students in the School's administration program.

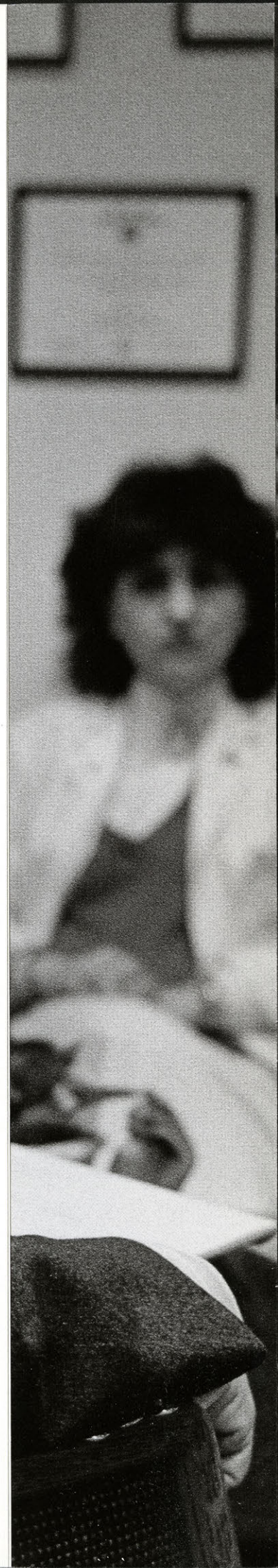
ADMINISTRATION PROGRAM

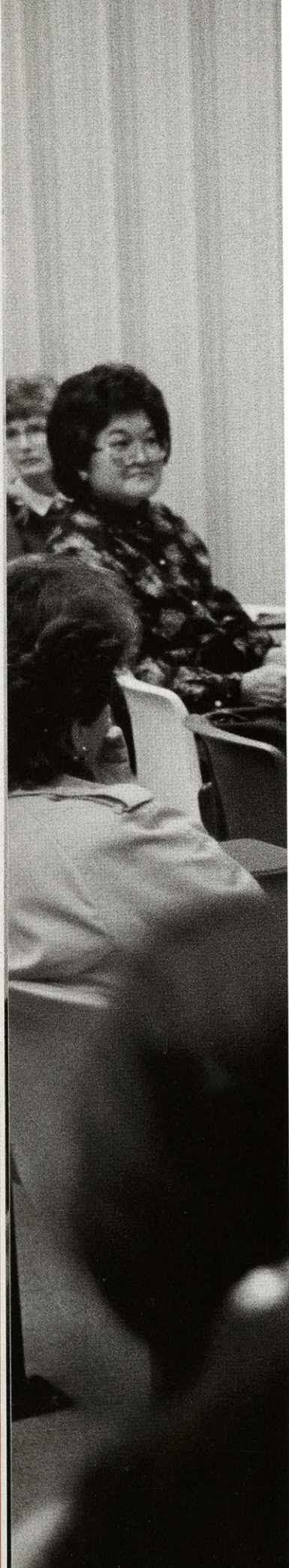
Recognizing that top and middle management opportunities for qualified nurses are increasing, the School of Nursing has made a profound effort in the last few years to consolidate and strengthen its administrative programs in order to better prepare its students for the challenges they will face. The two graduate programs in administration—one a Master's Degree and the other a DNS—are designed to prepare graduates to become leaders in clinical service and academic settings, as well as in policy-making positions of various kinds.

"Only a few years ago," says Marilyn Flood, associate dean, academic programs, "graduate students in the School's administration program could choose one area in the health care field to specialize in and focus on that in their studies. Now, however—with today's health care organization offering many different levels of care ranging from acute inpatient care to long-term settings to ambulatory and home health programs—our students have to have at least a working knowledge of each of these health care settings. This is because they will, undoubtedly, practice in organizations that offer more than one service."

Long active as a member of the administration program's faculty, Dean Margretta Styles remarked recently: "It's not enough that we prepare our nursing students with greater scientific knowledge and with clinical skills for expanded and knowledgeable practices. Our graduates have told us—and we have heard them—that our students must understand such things as how organizations work, how to manage personnel, how to develop and defend budgets, and how to use computerized information systems."

The administration specialty additionally contributes to mixed clinical and management programs, which are tailor-made to each student's goals. Courses are designed to incorporate the language and perspectives of business, economics, labor relations, computer sciences and government. This recognizes the institutional reality that effective nursing management requires integration of clinical, research and management knowledge in decision-making.





Furthering its goal to become *proactive* rather than *reactive*, the School selected a Blue Ribbon Panel two years ago to study the program and make recommendations. Composed of ten nursing leaders from different health-care settings throughout Northern California, the panel studied the program in relation to the need for it to be preparing excellent nursing leaders and managers for the future, as well as the present. A number of substantive recommendations were made—most of which have already been implemented.

One recommendation was that the program be directed by a nurse-leader with known and respected credentials in administrative research. In January, 1986, Virginia Cleland was appointed professor and director of the program.

The panel also encouraged the School to continue its practice of exposing students to the realities of the health care field of today and to the ever-increasing opportunities which exist for well-prepared nurses. One way the School has done this is to invite major health care leaders from throughout the country—such as Carolyn Davis, former director of HHS's Health Care Financing Administration—to participate in special programs and seminars. Additionally, a wide variety of people from many different management positions teach as members of the School's adjunct faculty.

Programs such as these illustrate how nurses have assumed top management positions, by introducing students to such nurse leaders as Eleanor Claus, chief executive officer at Alta Bates Hospital, and Anna Mullens, vice president for nursing at Children's Hospital, San Francisco.

Says Mullens—who chaired the Blue Ribbon Panel and is herself a graduate of the School's doctoral program: "The School is doing a tremendous job in preparing nurses to assume leadership roles in the emerging health care delivery system, which includes the shift from institutional to non-institutional systems like HMOs, home health and other programs."

Adds Flood, "As the field becomes more competitive and more complex, there are more opportunities than ever for nurse administrators. They bring with them a very special commodity in that they understand both the clinical nuances and the financial realities, and can therefore make or recommend decisions that take both aspects into account."

Nurses can be influential advocates for patients and the profession . . . they can design care delivery systems . . . negotiate tomorrow's health care policies and plan with administrators and other providers . . . and they can promote research that improves health care.

According to Flood, the crucial difference between nurse administrators and other health administrators is that nurse administrators more easily keep a focus on the patient perspective and put both the disease and its treatment in context.

"Nurses have the expertise," says Flood, "and the understanding of care delivery that allow them to take advantage of opportunities to make change for the better in the whole picture . . . not just for the economics of the 'bottom line.'"

And she adds: "A particular challenge for nurse-administrators today is that we must think about the patients that will need to be served in ten years and be sure that our institutions are still here to serve them in the best possible way."

Of the many challenges facing those in the nursing profession today, Mullens concludes: "With all the changes that are being made now because of DRGs and prospective payment—and with all the implications these changes will have on the future of health care delivery—it is important that nursing take advantage of the tremendous opportunities which exist now to influence the new directions in health care systems.

"We are at the point in the development of our profession where we can look at where we want to go in the health care industry and market ourselves as leaders, not followers.

"But," she warns, "we have a very narrow window of opportunity to do this. My guess is that we're in the third year of a five-year process and we'd better not let the opportunity slip by. If we do, we will have suffered a major loss."



CLINICAL NURSE SPECIALISTS

In a speech given more than 40 years ago, the late Frances Reiter, well-known nurse-educator, used the term “nurse clinician” to describe the type of nurse she felt was needed by both patients and the nursing profession.

Twenty years later in the mid-1960s, she wrote more fully about her concept of such a role. Basically, it was her belief that such nurse clinicians should care for, cure and counsel their patients, and that they would be distinguished from staff nurses by their increased responsibility, authority, accountability and control.

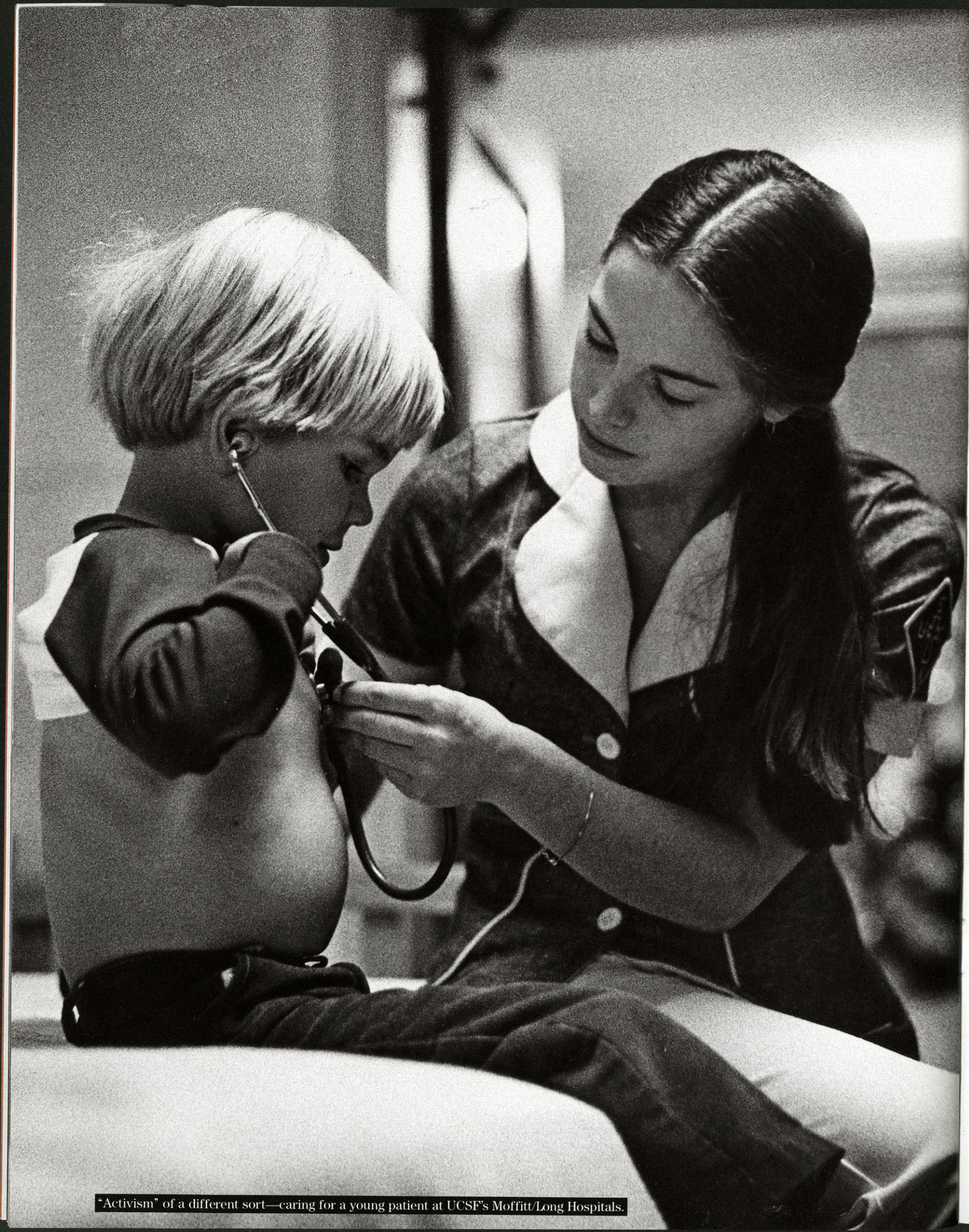
Today, 17 master's and doctorally-prepared clinical nurse specialists at UCSF hospitals are doing everything that Reiter dreamed of . . . and more.

Providing primary and intensive care in a wide range of clinical specialties, these nurses—seven of whom have earned their advanced degrees at UCSF's School of Nursing—report directly to Helen Ripple, associate director of UCSF Medical Center and director of nursing, as well as associate dean of the School of Nursing. Since coming to the UCSF campus in 1980, Ripple—a strong advocate of nursing specialization and of higher education for nurses—has both strengthened and expanded the role of clinical nurse specialist at UCSF. Indeed, as the evolution of this role in the nursing profession has unfolded over the last twenty years, UCSF School of Nursing and the Medical Center at UCSF have played a prominent national role in nurturing and developing it to its fullest capacity.

“Perhaps one reason the position of clinical nurse specialist has made such strides at UCSF,” says Ripple, “is the strong commitment and support it has gotten both from those in the School of Nursing and in the Department of Nursing Service. And, since Dean Styles and I share administrative and clinical positions in each other's bailiwicks, we're able to oversee its development in a mutually productive and collaborative way.”



Helen Ripple meets frequently with clinical nurse specialists at UCSF.



"Activism" of a different sort—caring for a young patient at UCSF's Moffitt/Long Hospitals.

One highly visible way in which the School and the Department of Nursing Service have collaborated is in the sponsorship of an annual conference given in San Francisco, attracting nurse leaders from around the country. The conference has been held each year since 1980 and has featured keynoters and faculty members of national renown—including Leah Curtin, Myrtle Aydelotte, Margretta Styles, Margaret Sovie, Roxanne Spitzer, Virginia Cleland, Susan Terkle and Rheba de Tornayay.

And—as a further sign of the times—topics have dealt with the complex challenges which clinical nurse specialists and administrators face in light of the current economics in health care delivery.

“Conferences such as the ones we put on,” Ripple says, “bringing together top leaders in all areas of the health care industry, are one way to help these nurse leaders remain well prepared to maintain their vital role on the health care team of the future.”

At UCSF, clinical nurse specialists have four areas of responsibility which predictably—due to the nature of patient care—often overlap. These include providing their clinical expertise in direct patient care situations, including patient and family education; serving as consultant to nursing staff on the units; conducting research in their chosen specialties, either on an individual or collaborative basis; and teaching at the School of Nursing or in the education department.

In addition—perhaps more so than their colleagues at other institutions—UCSF clinical nurse specialists are given more financial and administrative responsibilities, reporting on these matters directly to Helen Ripple.

Pamela Minarik, psychiatric liaison at UCSF's Medical Center, says, “One of the most gratifying things about being a clinical nurse specialist is being able to work collaboratively with nurses, especially any of the other 16 clinical nurse specialists, and to draw on their particular area of expertise.”

Minarik says that one reason this overlap is made possible at UCSF is that the position has been created to be specialty and service-based, rather than unit-based.

“And,” she notes, “the resulting autonomy, flexibility and appropriate priority setting are based on our assessment of clinical needs of the patient, family and nursing staff.”





"For example, Carol Viele—who is the clinical nurse specialist in hematology/oncology—and I often work together helping cancer patients and their families deal with the many different physical and emotional aspects of their disease. A year ago, we had a woman patient with terminal cancer who had undergone a colostomy. During this time, Carol—whose research interests include venous access devices, intraperitoneal chemotherapy and bone marrow transplant—worked very closely with her, along with me and Susan Barbour, a clinical nurse III, who was doing a special project in ostomy care at the time.

"When the time came for our patient to go home, the three of us worked out a plan which let us continue helping her at home with her learning needs and medical/nursing needs—as well as helping to keep her spirits up and help her and her family cope with her impending death. We even arranged to drop in for afternoon visits over tea, which we learned later from her husband was a terrific boost to her."

Noting that this was an unusual situation, Minarik says, "It shows, nevertheless, how we are able to create new ways of providing nursing care and—most importantly—offering a continuity and consistency throughout a patient's illness."

Recognizing that this was a unique situation and seeing the effect the nurses had had, the family of this woman has established the Sophie Robinson Memorial Fund, aimed at funding such home visiting programs by skilled clinical nurses for other terminally ill patients.

Says Lori Howell, clinical nurse specialist in pediatric surgery, "Often the greatest impact clinical nurse specialists have on the nursing profession occurs when we wear two or three of our different 'hats' at the same time, such as sharing the results of research projects directly with clinical nurses. Then they can put this information or skill directly to work with their patients.

"For example, I've focused my energies in planning the transition from hospital to home for children with tracheostomies. The literature has reported anywhere from 10 percent to 40 percent mortality in children less than one year of age once they get home, but we've discharged 15 such children and haven't had any deaths. That's partly because we've been able to educate the nursing staff—and the families of the patients—in procedures for changing the trach, doing CPR, and reading the monitor. With the nursing staff able then to reinforce what's been taught, the chances are much better that the family will return

home well-equipped to care for their child. So, in this particular example, I wore my research hat, my patient care hat and my teaching hat.

"All in all," continues Howell, "what clinical nurse specialists attempt to do is to work themselves out of a job by passing on a particular body of knowledge and expertise to other staff nurses. Of course, with the steady generation of new technology and research, along with the normal turn-over of staff, the chances of this ever happening are mighty slim!"

Clinical nurse specialists Lori Howell and Elizabeth Tong appreciate the fact that at UCSF they are not geographically bound to one area or unit.

For Tong—who specializes in pediatric cardiology with a special focus on the impact of congenital heart disease on the family—knowing that she can call on the special expertise of her colleagues is of great help.

"We all try to let each other know what we're doing and what we can do to help out," she says, "because we can't be an expert on everything. We also try to teach the nursing staff about this kind of collegial networking and teamwork.

"Knowing that Lori has an in-depth knowledge of wound care and healing helped me recently when I was working with a nine-year old boy who had undergone open heart surgery for a complex cardiac defect. Unfortunately, his recovery was complicated by congestive heart failure and subsequent fluid leakage. This, among other things, led to decreased perfusion and skin breakdown. It was also especially difficult on the family since they were not only dealing with a life-threatening operation, but now had the additional stress of secondary problems and a longer than anticipated hospital stay. In addition, his parents were divorced and from out of the Bay Area.

"Anyway," Tong continues, "I asked Lori to see the child, and she set up a special plan of care for him to promote healing and prevent further skin breakdown. She also had him transferred to a special bed to prevent pressure sores. We both realized that this was going to be a long-term patient, so we asked the unit nursing staff to assign him a primary nurse to increase continuity of care for the child and his family."

Eventually the boy recovered and went home with his mother, who—by the time he left the hospital—had become proficient in caring for his wounds and changing dressings.

Says Tong: "Clinical nurse specialists are basically the one facet of nursing care where knowledge and experience from many disciplines join together to provide the scientific basis for nursing care."





It was one of those lucky coincidences that Brigid Doyle started her new job as clinical nurse specialist in cardiology at UCSF in 1980 the same day that Moffitt Hospital got its new intra-aortic balloon pump.

Doyle—who had spent the previous year teaching cardiovascular nursing at UCSF's School of Nursing—had become intimately familiar with the pump while she was a staff nurse at Mercy Hospital in Des Moines. The pump is a highly complex piece of equipment used in coronary care units or catheterization labs as a temporary support system in the care and management of cardiac patients.

"Part of our responsibilities as clinical nurse specialists," says Doyle, "is to educate nursing staff. The balloon pump happens to be something I've worked with a long time and it is a good example of how high-tech hospital care has become. Not every nurse *likes* the technical and mechanical responsibilities that go along with working with machines like this. I am comfortable with it and like teaching others who are interested. These patients and their families become part of my case load. I explain to them what is going to happen and help prepare them for the experience emotionally. A large part of my job is to follow these complex patients and their families throughout their hospital course. They may move from the coronary care unit, to the catheterization lab, to surgery, then to the intensive care unit, and finally out on to the general nursing floor. I provide continuity of nursing care wherever they're located. This exposure to the patient and the patient's family helps particularly when planning for discharge and making arrangements for follow-up nursing care in the home."

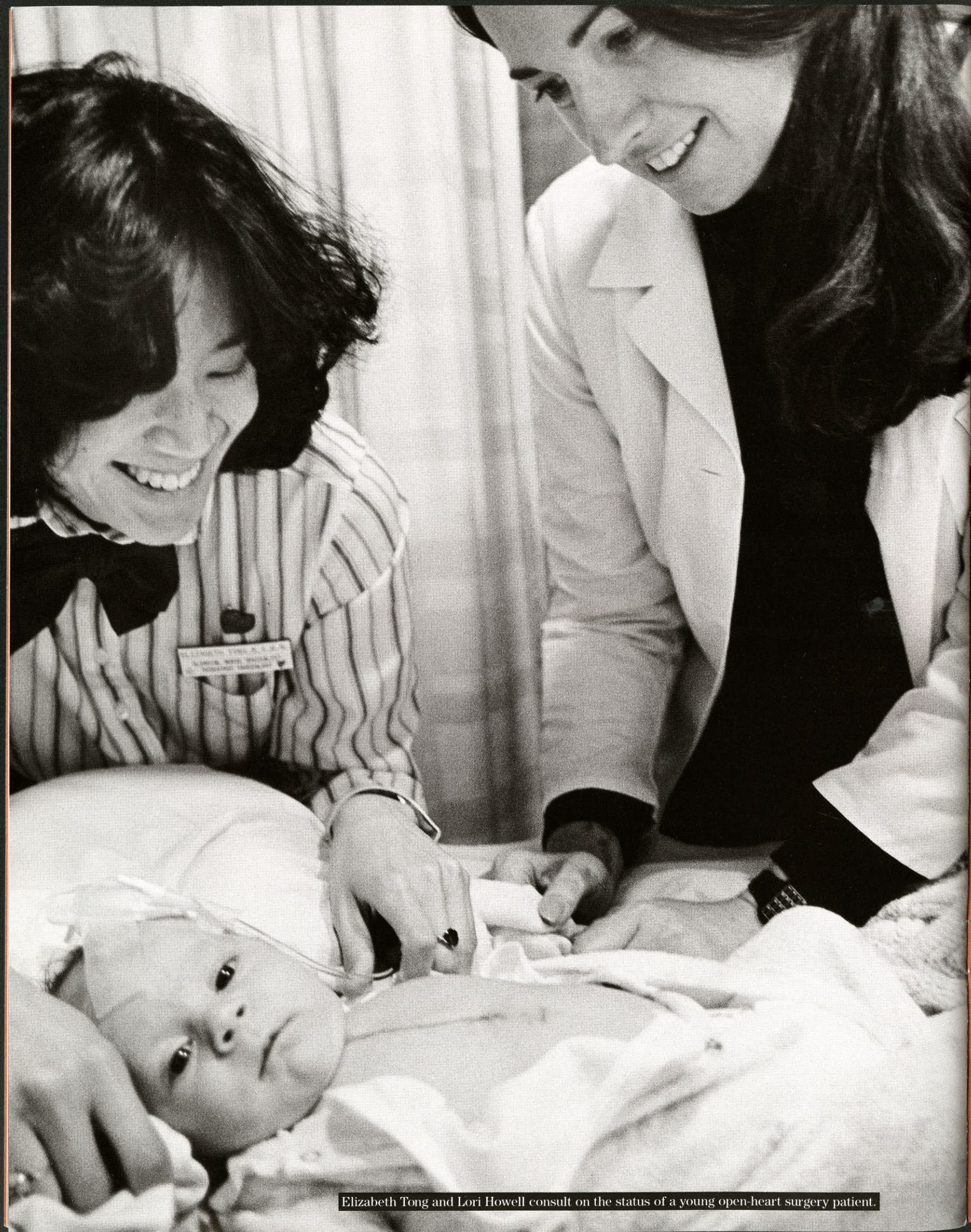
Although the physician inserts the balloon through the femoral artery, trained nurses are the ones responsible for setting up and running the machine, as well as monitoring the intravascular tubes. Stabilizing the patient can take up to three hours.

"When I first came to our CCU, no one else on the nursing staff had worked with this type of pump," Doyle continues. "At UCSF where there are now more than 50 of these procedures done each year, it is critical that we have a core of well-trained nurses able to take care of patients on the pump."

In the last three years, Doyle has certified more than 25 nurses to run the machine. It's just one part of her job—but it's clearly a favorite.



A large part of Brigid Doyle's job is training nursing staff in the use of the intra-aortic balloon pump.



Elizabeth Tong and Lori Howell consult on the status of a young open-heart surgery patient.

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