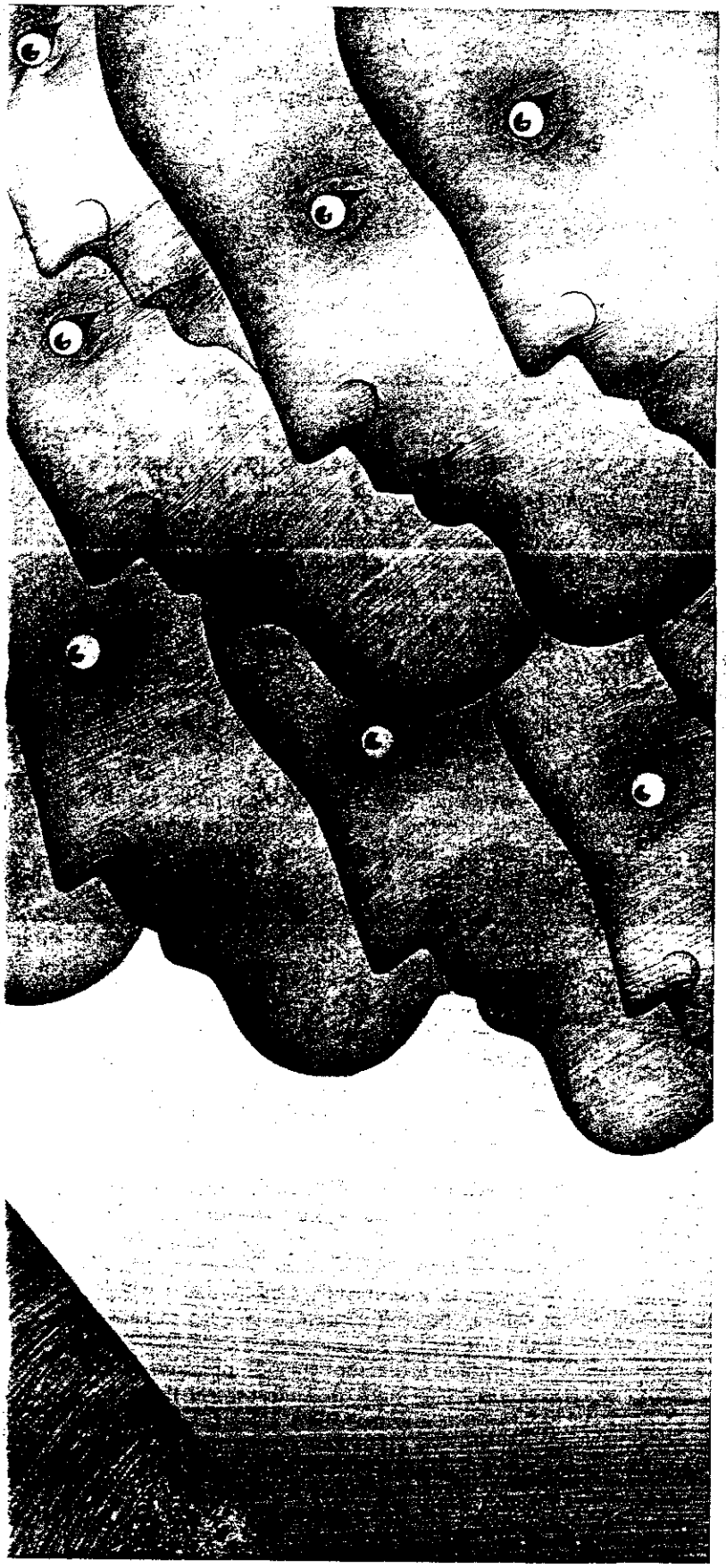
–like an open book?

ABSOLUTELY NOT CONFIDENTIAL



By Clark Norton

SKIING CROSS-COUNTRY through a campus park one winter's day, University of Michigan graduate student Frank G. Palermo* found himself perched atop a steep slope. Heart racing, he pushed off and sped downhill, only to come to a wrenching halt when his ski tips dug abruptly into the thin crust. The leather strap on his left ski pole snapped; so did his left thumb. Palermo wound up at the University Hospital in Ann Arbor, where his doctors decided to operate. In preparation, they summoned his medical records from his family physician in Detroit.

According to Palermo's file, he was a walking medical minefield. "You appear to have had your gallbladder removed at age two," the doctors told him. "You've had kidney stones, a broken nose, and recently broke your leg." Palermo was perplexed; except for the broken nose, the list of maladies was news to him. A phone call solved the mystery: It seems his family doctor had carelessly lumped his medical history in with those of his grandfather and cousin—both also named Frank G. Palermo.

Palermo laughs now about the snafu. But imag-

Illustrations by **James Endicott**

*This name has been changed.

ine another scenario, one that easily could have occurred had he not been able to set his medical records straight: Palermo applies for individual health insurance and signs a standard waiver authorizing the insurer to obtain copies of his medical files. With a supposed history of internal disorders and broken bones dating back to age two, he's clearly a bad risk and his application is rejected. Meanwhile—again acting on the waiver Palermo signed—the insurance carrier feeds its findings to a computer bank that shares medical data with hundreds of other insurance companies.

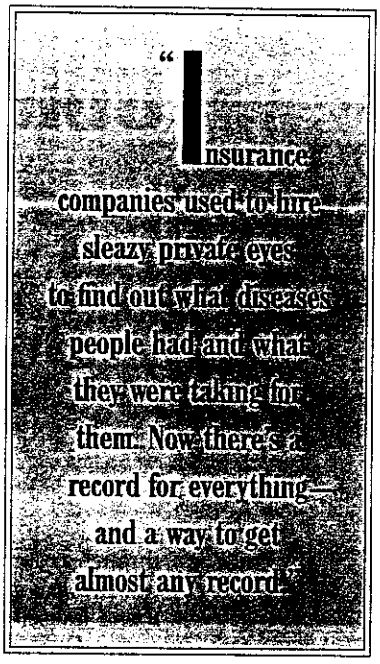
Now say that his grandfather or cousin had problems more controversial than gallstones or a broken leg. Some psychiatric care, perhaps. Drug abuse. Or—an increasingly daunting prospect today—a positive test for HIV, the virus associated with AIDS. In addition to being rejected for insurance, Palermo suffers a series of unaccountable setbacks. He applies for a postgraduate program—and is turned down. He sends out job applications—and is never called for an interview. And when Palermo finally lands a second-rate job, his co-workers buzz about his "condition." He loses any chance of career advancement. Palermo never suspects that it is his medical records—leaked to the world, containing mistakes he doesn't even know about—that have left his life in a shambles.

Palermo was lucky; he was able to head off trouble. But if you don't know what's in your own medical records and who has access to them, you might find yourself in just such a horror story.

"More and more people are demanding your medical records," says Stuart A. Wesbury, president of the American College of Healthcare Executives. "Attorneys. Employers. Insurers. Government agencies. Media."

"Insurance companies used to hire sleazy private eyes to find out what diseases people had and what they were taking for them," says Evan Hendricks, publisher of *Privacy Times* newsletter in Washington, D.C. "They don't need to do that any more. There's now a record for everything—and a way to get almost any record." This point was dramatically illustrated in November 1986, when a reporter somehow obtained the medical record of the late right-wing lawyer Roy Cohn from the National Institutes of Health and published it in *Harper's* magazine, complete with information confirming that Cohn had AIDS.

The awful irony is that depending on where you live, you may have far more difficulty getting your medical records than would any of those groups on Wesbury's list. Twenty-one states currently have no law guaranteeing patients access to their hospital and physicians' office records. Only 23 states and the District of Columbia let patients see both kinds of records. And even in those states, obtaining records can be so costly or time-consuming that many people give up in frustration.



LIKE MOST AMERICANS, you've probably assumed your medical records were confidential—protected by ethics and the law. At one time, you would have been right.

"We used to have a medical system that was confidential," says retired Harvard School of Medicine neurosurgeon Vernon Mark, whose father, grandfather, and great-grandfather were also physicians. "The patient went to a doctor, the doctor made a diagnosis, and the diagnosis stayed with the doctor. My father used to treat a lot of people who had sexually transmitted diseases. For him to reveal that kind of information would have been unthinkable."

Though physicians still swear an oath not to reveal patient information, old-fashioned medical confidentiality has become a notion quaint as the house call—gradually eroded by court decisions and a victim of the industrialization of medicine.

The courts have ruled, for instance, that when the welfare of society is at stake, medical information can be released without the patient's consent or knowledge. In the case of sexually transmitted diseases, as an example, doctors are now required to report patients who have venereal disease to state public health departments. In most states, doctors also must report gunshot wounds or cases of suspected child abuse. Psychiatrists often are required to alert the police if they believe a patient is dangerous. The courts have ruled that hospital review boards may use patient records to flush out bad doctors. Researchers rely on medical information for public health purposes such as tracking down Legionnaire's disease. Lawyers frequently depend on medical records to document cases of malpractice. Police and grand juries are sometimes permitted to use records to gather medical evidence to catch or indict criminals.

But privacy has fallen hardest to the demands of the big business of medicine. Insurance companies, employers, and government agencies now foot an estimated 70 percent of all the medical bills in this country. They want to know where their money's going, and to find out they scrutinize the records that doctors and hospitals keep on all of us.

To be sure, much of this record-sharing is legitimate, even beneficial. Who could argue with the need to ferret out child abusers, to uncover fraudulent doctors, to hold down medical costs? University of Chicago surgeon Mark Siegler says these exceptions to total medical confidentiality, which he calls a "decrepit concept," have led to better health care for all.

The trouble is that the demands for information have grown so much that the orderly flow has become a nearly unchecked torrent. In a single month, the Stanford University Hospital medical records department receives 1,500 requests for medical records information—from insurers, phy-

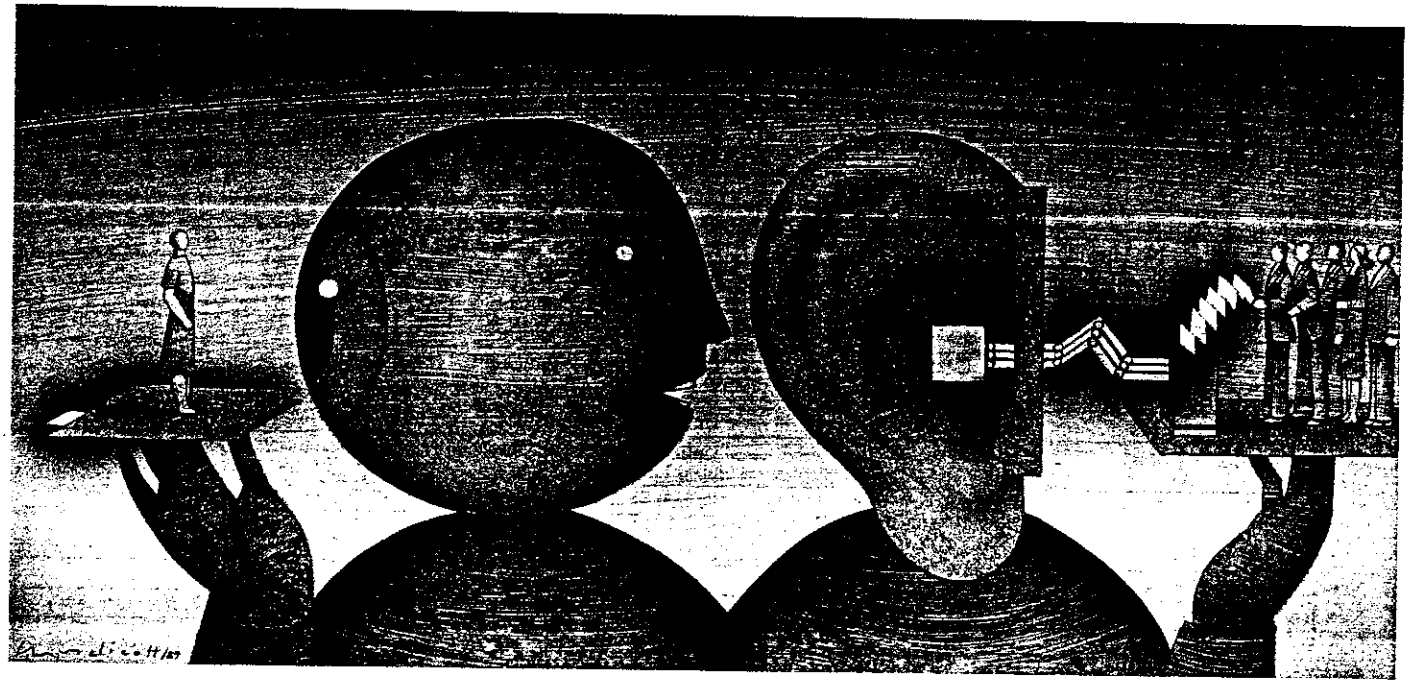
sicians, attorneys, federal and local law officers with subpoenas, and other sources.

YOU MAY BE THE ONE who unknowingly starts the flood. For the privilege of having health insurance, you most likely have signed a waiver on a claim form that says something like this: "I authorize any physician, hospital, or other medical provider to release to [name of insurance company] any information regarding my medical history, symptoms, treatment, examination results, or diagnosis." With that in hand, if your insurer wants to know why your doctor charged $600 for a physical, it can delve into your records without telling you.

And that's one place where the leaks may start springing: The doctor's office can turn the insurer's request into a breach of confidence, simply out of expediency. As San Francisco personal injury lawyer Bennett Cohen explains, "If an insurance company wants records to see if someone has an asthma condition, and that patient also saw the same doctor for a VD infection five years ago, the insurer gets that information, too. No one in the doctor's office is going to go through fifteen visits and segregate out the records relevant to asthma, and—legitimately, I suppose—the insurer doesn't want to rely on a nurse or receptionist to figure out what's pertinent to what."

Hospitals, too, may release more than the insurer needs to know, barraged as they are by requests for records. "It's up to the hospitals to ask insurance companies, 'What do you need that for?' " says Wesbury. "But each policy is a little different. It's very difficult to identify precisely what information is needed." Hospitals also contribute their own unique leaks. "Charts travel all over," says Molly Cooke, an internist and head of the ethics committee at San Francisco General Hospital. "Thirty to forty people may look at one during treatment: X-ray technicians, dietitians, occupational and physical therapists, social workers, medical students, pharmacists. If the patient has an unusual illness, the number may be much higher. And the fact is that total strangers could also look at charts, the way most hospitals leave charts lying around. Then there are the 'elevator conversations' among doctors—who because they're in a hospital simply forget they're talking about someone in public."

In practice, your records may not even go directly from the doctor or hospital to the insurance company. Many insurers use a consumer reporting agency, which also gathers information for groups such as mortgage lenders and marketing research firms, to collect authorized records from doctors and hospitals. One such company, Equifax Services, handles 1.5 million transactions per day for its 60,000 customers, which include all the major North American insurance carriers. Equifax says it doesn't keep any of the medical information it collects for insurers. However, such firms depend on computers and sometimes on computer data banks—none of which has ever been heard to utter the Hippocratic Oath, and all of which may invite electronic break-ins.



One data bank that has long given consumer advocates the willies is the Medical Information Bureau, a Boston-based nonprofit association representing about 800 of North America's insurance companies. The bureau stores computerized medical data—and some nonmedical information such as bad driving records or hazardous hobbies—on 13 million North Americans. If you have ever filled out an application for individual health or life insurance, or for additional coverage on your group

Can You Get Your Medical Records?

State	Doctor	Hospital	Mental Health	Comments
Alabama	No law	No law	No*	*Records releasable by court order
Alaska	Yes	Yes	Yes	
Arizona	No law	No law	Yes*	*Unless harmful to patient
Arkansas	No law	No law	No law	
California	Yes	Yes	Yes	
Colorado	Yes	Yes	Yes*	*Unless harmful to patient
Connecticut	Yes	Yes	Yes	
Delaware	No law	No law	No*	*Records releasable to attorney or by court order
D.C.	Yes*	Yes*	Yes**	*Access guaranteed by case law, not state law **Unless harmful to patient
Florida	Yes	Yes*	Yes	*Except psychiatric progress notes and consultation reports
Georgia	Yes	Yes	Yes	
Hawaii	Yes	Yes	Yes	
Idaho	No law	No law	Yes*	*Applies to patients of state institutions; unless harmful to patient
Illinois	Yes	Yes	Yes	
Indiana	Yes	Yes	Yes	
Iowa	No law	No law	Yes	
Kansas	No law	No law	Yes*	*Unless harmful to patient
Kentucky	No law	No law	Yes	
Louisiana	Yes	Yes	No*	*Records releasable to attorney or relative
Maine	No law	Yes	Yes*	*Patient may have to be supervised while reviewing records
Maryland	No*	Yes	Yes	*Release is at doctor's discretion
Massachusetts	Yes*	Yes	Yes*	*Unless harmful to patient
Michigan	Yes	Yes	Yes*	*Unless harmful to patient
Minnesota	Yes*	Yes	Yes	*Unless harmful to patient
Mississippi	No law	Yes	No*	*Patient authorizes release, but law doesn't specify release to patient directly
Missouri	Yes	No law	Yes*	*Unless harmful to patient
Montana	Yes*	Yes*	Yes*	*Uniform Health Care Information Act passed in 1987; unless harmful to patient
Nebraska	No law	No law	No*	*Patient authorizes release, but law doesn't specify release to patient directly
Nevada	Yes	Yes	Yes*	*Patient allowed to see records at least every three months; unless harmful to patient
New Hampshire	No law	No law	No law	
New Jersey	Yes	Yes*	Yes	*Access guaranteed by state department of health regulation, not state law
New Mexico	No law	No law	Yes*	*Unless harmful to patient
New York	Yes	Yes	Yes	
North Carolina	No law	No law	Yes*	*Unless harmful to patient
North Dakota	Yes	Yes	No	
Ohio	No law	Yes	Yes*	*Unless harmful to patient
Oklahoma	Yes	Yes	No*	*Patient not entitled to records unless court-ordered, but practitioner may consent to release
Oregon	No*	No*	Yes**	*Release is at discretion of private institutions and doctors; public institutions must release records **Unless harmful to patient
Pennsylvania	No law	Yes	Yes*	*Unless harmful to patient; patient may have to be supervised while reviewing records
Rhode Island	No law	No law	No law	
South Carolina	No law	No law	No law	
South Dakota	Yes	Yes	Yes*	*Unless harmful to patient
Tennessee	No law	No*	No**	*Patient must show "good cause" to get records **Patient can designate person to receive records
Texas	Yes*	Yes	No law	*Unless harmful to patient
Utah	No*	No*	No**	*Releasable to attorney **Releasable to family or friends
Vermont	No law	No law	No law	
Virginia	No law*	No law*	Yes**	*In a lawsuit, patient has right to records; attorney general opinion extends this right to non-suit situations **Unless harmful to patient
Washington	No law	No law	No*	*Patient can designate person to receive records
West Virginia	Yes	Yes	Yes	
Wisconsin	Yes	Yes	Yes	
Wyoming	No law	No law	No law	

A "yes" in any column means state law specifically guarantees patient access. A "no" means state access law doesn't include patients. The comments column gives restrictions. Other hurdles, such as copying fees, usually exist. Don't give up if you live in a state that has no law or doesn't grant access. Your doctor may let you see your records anyway. If not, have them sent to a more cooperative physician. Or get a lawyer to make the request for you. If your records are kept by a federal facility, such as a VA hospital, you're guaranteed access.

Hippocrates research by Mary James.

insurance plan, you may be on file.

Here's how the system works: When you apply for insurance, you sign an authorization (this is different from the claim form waiver) allowing the company to gather material on you from sources such as the Medical Information Bureau, government agencies, consumer reporting groups, even interviews with neighbors. Your application will say whether that insurer uses the bureau.

If the company finds anything it thinks might interest other insurers—weight, blood pressure, electrocardiograph readings, and X-ray results are among the most common items—it feeds the data to the bureau. Later, upon request, the bureau relays the information to any other member company; except for government agencies with a subpoena, only member companies can use the data. The bureau doesn't check the information for accuracy, and it stays in the computer seven years.

While the Medical Information Bureau runs the "Big Computer in the Sky," as one attorney dubs it, your fellow employee or office supervisor may present an even more immediate threat at the video display terminal down the hall. With computers enabling employers to handle claims in-house, four-fifths of the nation's 1,500 largest firms now run or finance their own insurance programs. That means that when you submit a claim, the personnel office, and maybe your boss or others, will discover that you have had, say, an abortion. Some larger companies now have safeguards such as separating employee medical records from other records.

More than privacy is at stake here. Chicago psychiatrist Jerome Beigler, former chairman of the American Psychiatric Association's Committee on Confidentiality, says that his investigations found several cases across the country in which schoolteachers had been fired or demoted after undergoing psychiatric treatment billed through their employers' insurance. "The irony is that those with the courage to get treatment jeopardize their careers," Beigler says, "while others who could be much worse off take it out on their students instead." An estimated 15 percent of all employees with company-run insurance programs pay for covered psychiatric treatment themselves, because they fear repercussions from their employers.

Similarly, Los Angeles substitute teacher Allan Rodway's decision to take an AIDS test before marriage cost him his job—and more. According to the lawsuit Rodway filed, the University of Southern California Hospital mistakenly told the Los Angeles School District that Rodway had AIDS, causing him to be suspended. California law prohibits releasing such information without written patient consent. Rodway regained his job through out-of-court negotiations, after his doctor wrote a letter stating that the teacher did not have AIDS. Even so, according to Rodway's deposition, the disclosure caused his fiancée to leave him and his church to shun him.

An employer or insurance company may not

THEY'VE GOT A FILE ON YOU

CHARLES ZIMMERMAN probably could have gotten disability insurance without any trouble if he hadn't bragged about his healthy habits. But when an investigator for the insurance company asked the 32-year-old Boston engineer whether he smoked, "I proudly said, 'I have a very clean lifestyle—I don't smoke or drink,'" says Zimmerman. "I thought he'd be impressed."

Instead, he was . . . interested. Never drank? Did Zimmerman ever attend Alcoholics Anonymous? Zimmerman, being an honest sort, said yes. And was denied insurance. He applied to a second insurance company, and was offered coverage for 25 percent above the normal rate. That's when Zimmerman learned there was a file on him at the Medical Information Bureau, the data bank used by the country's major life and health insurance companies. In that file there was a little symbol that meant Zimmerman was an alcoholic.

Now, as Zimmerman says, he doesn't know if he can rightly be called an alcoholic. Drinking had never threatened his job, had never led to any medical or legal problems. He had simply decided, six years ago, that he was drinking too much, and had done something about it. "I told them, 'There is no medical history here—my only symptom ever was a hangover.'"

Zimmerman eventually got insured at normal rates, and—though it took a year—he also got the bureau to remove the disputed symbol from his file. But his experience highlights concerns about the data bank that holds information on about 13 million of North America's insured.

The Medical Information Bureau was founded in 1902 to guard against the wily applicant who, denied insurance at one company, would lie to a second in order to pass muster. It's a simple setup: If an insurance company finds an applicant has a health-threatening condition, such as high blood pressure or heart disease, it alerts the data bank. The bureau requires its members to independently verify all information. (A 1977 investigation found that 80 member companies had not been following this rule; now, says president Neal Day, such incidents are rare.)

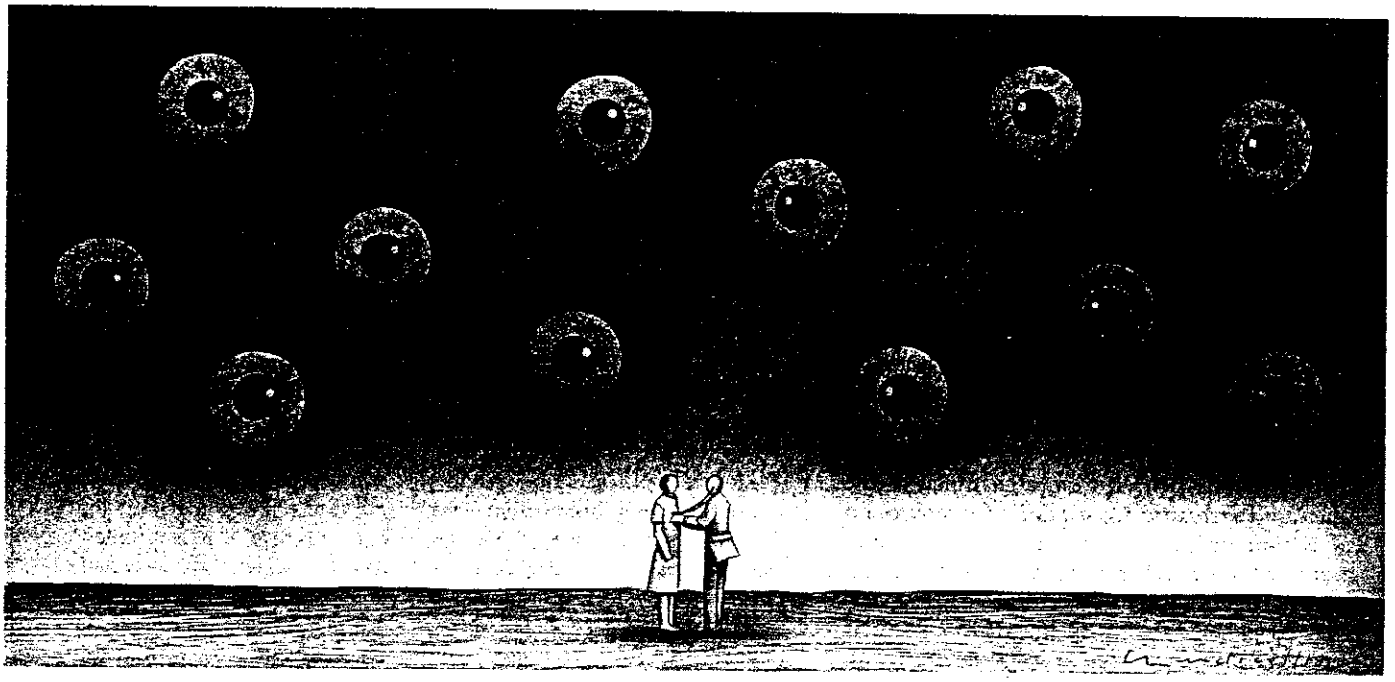
It's hard for an outsider to know whether these internal rules are followed, though, because the data bank isn't stringently regulated. According to privacy experts, most state laws governing the bureau lack punch, if they exist at all. On the federal level, the Fair Credit Reporting Act would empower a rejected applicant to find out just what is in that file—except that the act specifically excludes medical information. That leaves self-regulation. According to Day, the agency acts as though all its dealings were covered by the Fair Credit Act.

By the grace of the bureau, then, you can find out what's in your file. It will send you a form that asks for your name, birthdate, birthplace, present address, and a promise, under penalty of fines and imprisonment, that you are who you say you are. When you return the form, it'll send you, within 30 days, any nonmedical information it may have on you—for instance, that your medical records note that you're a skydiver. Any medical information goes to a health care professional of your choice.

If you find any mistakes, there's a simple procedure to follow—although Zimmerman's experience shows that it's not always a speedy one. First, the agency will ask for a re-investigation by the insurer that originally filed the erroneous information; you may want to send the insurer a statement from your doctor. If the bureau decides you're correct, it will make the appropriate changes. If you're dissatisfied with the response, your only recourse is to send the bureau a statement of dispute, which will become an inseparable part of your file.

Write or call: Medical Information Bureau, P.O. Box 105, Essex Station, Boston, MA 02112, 617/426-3660. —*Lisa Davis*

even be the last stop in the journey of a runaway medical record. It wouldn't be hard, say privacy experts, for those not involved in your health care to get their hands on your records: The ubiquitous use of computers and data banks, and the frequency with which records are passed among insurers and employers, offer plenty of chances for someone to intercept private information. (The Medical Information Bureau, however, is well known for its thorough computer security, and Equifax says that none of its medical information is stored in data banks.) Experts suspect interception happens, but have little real evidence. In 1983, though, a group of Wisconsin teenagers proved that it could when they electronically gained access to some 6,000 records at New York's Memorial Sloan-Kettering Cancer Center. The consequences might have been disastrous: Among other duties, the computer helped regulate radiation doses for patients. Some have warned that medical snake-oil salesmen could similarly acquire computerized mailing lists of patients—organized neatly by ailment—to bombard the afflicted with pitches for quack remedies.



If you're thinking there must be laws that will protect you against such abuses, don't count on it. What exists on the federal level covers only federal agencies, such as Medicare, or federally funded programs, such as drug rehabilitation services. The Privacy Act of 1974, for example, does require federal agencies to get written patient consent before releasing records outside the agency. But an agency can get information from a doctor or hospital without telling the patient. And it needs no consent to pass someone's records around within the agency—the Centers for Disease Control could pass a record to the Alcohol, Drug Abuse, and Mental Health Administration, for instance, because both are part of the Public Health Service.

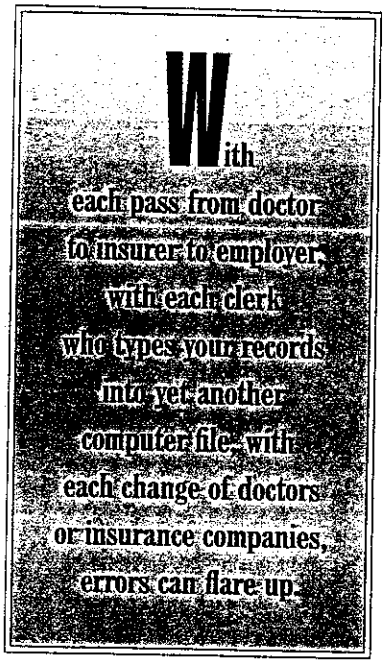
Employers and insurers are covered by state laws, but they are usually scattershot. In most states, doctors and hospitals cannot release a medical record without the patient's consent. An indiscreet doctor can lose his or her license or be sued. (However, that blanket waiver you sign on the claim form gives health care providers all the consent they need.) In Louisiana, hospitals and doctors have to give patients, on request, a copy of anything they have provided to any company, agency, or individual. About a dozen states—including Georgia, Illinois, and California—permit patients to inspect and copy insurers' records. Rhode Island requires that an insurer's authorization waiver must state that no disclosure will be made without patient permission. Alaska, Ohio, and Wisconsin let employees see or copy medical records held by their employers; Connecticut and Michigan let employees correct such information. But few, if any, state laws go beyond the employer or insurer. "The lack of control over what insurance companies and others do with records is the single biggest weakness in medical privacy law today," says Robert Ellis Smith, publisher of the *Privacy Journal* in Washington, D.C.

If the legal jumble seems like a bad dream, the possibility of mistakes can turn it into a nightmare. With each pass from doctor to insurer to employer, with each clerk who types your records into yet another computer file, with each change of doctors or insurance companies, errors can flare up like herpes and are just about as impossible to eradicate. No one knows how often mistakes occur, but they do happen: Out of the 7,000 patients who ask for their files from the Medical Information Bureau each year, 200 request corrections in their records.

Sometimes the damage—both physical and economic—from these errors can be devastating.

Midwesterner Scott Dillon* has been haunted by such a mistake for more than two decades. While attending medical school in the mid-1960s, Dillon, who was considering a career in psychiatry, opted to undergo psychoanalysis as a routine part of his training. During this time he visited the student health service for treatment of severe headaches and back pain. The doctor in charge, discovering that Dillon was seeing a psychiatrist, concluded that the pains were psychosomatic. Dillon was sent to a psychiatrist-in-training, who wrongly told him he was manic-depressive.

The diagnosis followed him like an insistent mosquito. Desperate to ease his pain, Dillon allowed doctors to give him powerful antidepressants and shock treatments. The effects were worse than the supposed illness. Dillon dropped out of medical school, and several graduate schools later rejected his applications. Worst of all, Dillon didn't receive the timely treatment he needed for what eventually were diagnosed as genuine physical ailments: severe allergies and a degenerative disease of the spine. As a result, he was left half-crippled. He later learned that the medical school had sent his medical record, complete with psychiatric diagnoses, along with his academic record to all the graduate schools to which he had applied. The misdiagnoses were eventually expunged from his record, but he believes he carries their stigma to this day.



IF YOU WANT TO HAVE ANY SAY about what's in your records and who gets them, here's what you have to do: Get a copy of your own medical records from your doctor and make sure they're accurate and complete. Before 1959, no court recognized that patients had the right to have access to their own medical records. Today, it may not always be easy to get your records, but at least you have a fighting chance (see page 56). "The issues of third-party access and patient access go hand in hand," says Smith of the *Privacy Journal*. "How can you give informed consent to insurance companies examining your records if you don't know what's in them?"

"Everyone should have a copy in their bureau drawer, and take them along whenever they go to the doctor," says Doris Haire of the Washington, D.C.–based National Women's Health Network. If something is inaccurate or missing, she says, you should go to the responsible doctor or hospital and ask for a correction. You may have to agree to undergo certain tests or examinations in order to remedy the mistakes.

You can also practice a little preventive medicine on your insurance policy. On the claim forms, try rewording the waiver this way: "I authorize my records to be released only from [the pertinent hospital or doctor] for the dates [the date of your hospitalization or appointment] as relates to [the condition covered by that claim]."

On the application, you can limit the authorization by adding a notation that says the company can obtain information only for the period up to and including the current date. That way, the company doesn't have perpetual permission to collect anything it wants, anytime it wants. Keep in mind, however, that insurers may tell you to take your business elsewhere. And, while George Annas of the Boston University School of Public Health says the technique works well for many, he also says, "If it's life insurance, they have you over a barrel. They want everything. And they won't insure you unless they get it."

Under the Federal Fair Credit Reporting Act, however, you are entitled to the sources of any medical information an insurer has used to deny you coverage. Likewise, you can get any information that the Medical Information Bureau may have on you (see page 57). Also, you might want to contact your local chapter of the American Medical Record Association (call 312/787-2672, extension 256) to learn whether your state has laws to help you get your records from employers, insurance carriers, and others.

One option that all states permit—albeit a rather drastic one—is to sue your doctor if you catch him or her red-handed in a breach of confidentiality. "But if you really want to keep your privacy, that's a self-defeating proposition," Annas says. "As soon as you bring a lawsuit, your record becomes public."

Perhaps the best news for your medical secrets is a model bill drafted by the National Conference of Commissioners on Uniform State Laws, a group that tries to iron out inconsistencies and gaps in state laws. (Each state can enact this law; it doesn't need ratification by a majority of states.)

The proposed law would allow patients to get their own records, require that anyone other than doctors or hospitals get patient consent before obtaining records, and limit access by subpoena. If outsiders couldn't present compelling evidence of need, records keepers could not be held liable for refusing their request. The act specifies some key exceptions—such as allowing access to bona fide researchers, financial auditors, or emergency rooms—that may leave open some of the same old loopholes. And it doesn't tackle the crucial problem of the release of medical information by insurance companies and others.

Montana is the only state to adopt the law so far, and while other states may soon follow, it's probably best not to wait on them. When it comes to protecting your own medical privacy, there's really only one good rule to follow: Don't count on anyone else to do it for you. H

Clark Norton is a freelance writer in San Francisco.

*This name has been changed.