

It could save thousands of lives and billions of dollars. One of our foremost authorities asks why we don't have . . .

THE CANCER WEAPON AMERICA NEEDS MOST

By JOHN H. HEALEY, M.D.

DONALD AUSTIN was astonished by what he saw that day in 1975. As chief of the California cancer registry, Austin directed one of the largest storehouses of local cancer statistics in the world, and researchers frequently consulted him about the incidence of the disease in the San Francisco area.

On this afternoon, Austin had been asked for a tally of all cases of breast, uterine and ovarian cancer. As his eyes skimmed the computer printout, he was startled by a disturbing trend: year by year, cases

JOHN H. HEALEY, M.D., is chief of orthopedic surgery at Memorial Sloan-Kettering Cancer Center in New York City.

of uterine cancer were climbing dramatically.

Austin found that since 1969, uterine cancer in the Bay Area had risen by 50 percent. Worse, the incidence among women age 50 and over from affluent Marin County had doubled. Why were these well-off women at greater risk?

It didn't take long to finger a possible culprit. Between 1965 and 1975, prescriptions of estrogen—the hormone used to treat symptoms of menopause—had tripled nationwide. Large doses (far larger than are prescribed today) were being given, mostly to affluent women over 50.

Many in the medical profession

doubted the link. To them, estrogen was a wonder drug. But to be safe, the Food and Drug Administration advised that women receive only the smallest possible dose and that doctors balance its effects with the hormone progesterone. Within three years, the rate of uterine cancer returned to normal. Thanks to a good cancer registry, at least 3000 women a year—in California alone—are spared.

WITH NO CANCER REGISTRY at their disposal, Massachusetts health officials were baffled by a sudden epidemic of cancer in Woburn, a Boston suburb. Only days after Anne Anderson's 3½-year-old son, Jimmy, was found to have leukemia, she learned that two other neighborhood children also had the disease. Then a fourth case cropped up. And when Anderson brought Jimmy to Boston's Massachusetts General Hospital for treatment, she was amazed to see a number of familiar Woburn faces in the waiting room. *Could there be something in Woburn that's giving leukemia to our children?* she wondered.

By October 1979, Anderson and her pastor, the Rev. Bruce A. Young, had tracked down 12 leukemia cases in Woburn—double the normal incidence. That same year, state environmental engineer Richard Chalpin suspected that toxic chemicals illegally dumped in Woburn had made their way into the water supply. He checked two municipal wells and discovered dan-

gerously high levels of an industrial solvent. Then Harvard professors Marvin Zelen and Steve Lagakos found that, on average, the children with leukemia had consumed twice as much contaminated water as other Woburn youngsters had.

Jimmy Anderson died in 1981, but his mother was determined to help other kids. That's when she and Bruce Young helped persuade the Massachusetts legislature to create a cancer registry. Clusters of the disease are now detected long before they become as widespread as the tragic Woburn cases.

THESE TWO BATTLES in the war against cancer illustrate how vital statistics can be. Ideally, researchers should be able to gather intelligence on all forms of cancer, not only because the disease is so widespread (one in three Americans are expected to contract some type of it in their lifetime) but also because it is infinitely complicated. It comes in dozens of different forms, and each cancer can have many causes—some inborn, others environmental. There are also dozens of ways to treat the disease. To battle such a beast, researchers need an exact statistical profile.

But many parts of the United States lack such information. Ten states have no cancer registries. Most of the others do not record all cases within their borders. And more than a third fail to record how patients are treated or whether they have been cured.

Back in the 1930s and 1940s, many states passed laws requiring health officials to keep track of cancer. But in almost every case, these laws went unfunded. (The notable exception was Connecticut, which has operated a model registry since 1935.)

Then, in the early 1970s, the National Cancer Institute began keeping accurate records for cancer patients in five states (Hawaii, Utah, New Mexico, Iowa and Connecticut) and four metropolitan areas (Detroit, Atlanta, San Francisco and Seattle). These SEER (Surveillance, Epidemiology and End Results) registries cover roughly ten percent of the nation's population. They are useful for making broad estimates of cancer rates. But because the registries ignore 90 percent of the population, they miss smaller trends such as the leukemia outbreak in Woburn.

Three years ago, the American College of Surgeons, with the help of the American Cancer Society, started a second national registry, the National Cancer Data Base, to track how well different treatments work. The data base covers only 30 percent of all cancer patients and misses victims cared for outside hospitals or in hospitals without registries.

Gilbert H. Friedell, director of Kentucky's state registry, uncovered exactly the kind of problem that neither SEER nor the National Cancer Data Base would have picked up. While reviewing state

statistics, he noticed that women in Kentucky's poverty-stricken Appalachian areas were dying of cervical cancer at twice the national rate. Friedell found that many women there were unaware of the importance of regular pap smears, which can detect cervical cancer when it is still curable. Kentucky officials have established a community outreach program to correct the problem.

Even if SEER and the National Cancer Data Base kept track of more cancer patients, they are not geared to spot local trends. By contrast, a good state registry can identify dozens of cancer clusters every year. Even when a cluster cannot be linked to some special circumstance, it is important that the public understand the situation.

Consider the 1990 scare in Taylorville, Ill., where neuroblastoma, a rare cancer of the nervous system, had stricken three infants. Such a rate was several times the expected incidence, and parents suspected the children had been harmed before birth by contaminants their mothers inhaled from a toxic-waste site. After extensive interviews, however, the Illinois State Cancer Registry determined none of the mothers had been at the site, and careful monitoring showed that no contaminants had made their way to the outside air. The town of Taylorville heaved a sigh of relief.

AS IMPORTANT AS the need for good registries is the need for uniform statistics. Unless data from all 50

READER'S DIGEST

states can be tallied, we cannot get detailed pictures of rare cancers.

Consider osteogenic sarcoma, or bone cancer. Even at major facilities like New York City's Memorial Sloan-Kettering Cancer Center, we cannot collect enough data to detect broad trends in the disease. But in Sweden, which operates an excellent cancer data base, orthopedists recently discovered that the mean age of people afflicted with bone cancer—generally considered a disease of growing bones—has gradually been increasing. Perhaps, then, we should be watching for a second variety of osteogenic sarcoma, caused by different genetic mechanisms than in the younger person's form of the disease. If we could track the cancer's path through the entire U.S. population, who knows what we might learn?

It would also be useful to track the rare side effects people experience from cancer therapies. Some reactions, such as the minor brain damage that can develop in leukemia patients who have received whole-brain radiation, occur many years after a patient is treated. So unless all cancer victims are followed for their entire lives, we cannot study these debilitating side effects and develop alternative therapies.

Why does the United States lag behind many other Western nations in gathering cancer data that could save thousands of lives and billions of dollars? Perhaps policy

makers have always assumed that money is best spent on research and patient care. Record-keeping pays off only well into the future, after data have been collected long enough to reveal trends. Thus we tend to gamble it won't be necessary.

Treating an advanced case of breast cancer, for example, may cost \$60,000 more than treating a case detected early. Good registries could save these costs by pinpointing areas where women are not getting mammograms or performing self-examinations.

Although not as glamorous, cancer tabulation can be more important in the fight against cancer than performing an intricate operation or an elegant experiment. A network of cancer registries can be our most potent new weapon against the disease.

The Cancer Registries Amendment Act of 1992 could solve this problem by enabling each state to have a registry operating under uniform standards. Cost to federal taxpayers would run about \$30 million.

The Cancer Registries Act—and funding to support it—is needed now. Please write your Senators and your Representative to urge creation of uniform registries.

People do not naturally rally round a cause like cancer record-keeping because no one can point to victims who will suffer without it. Rather, it is our larger understanding of cancer that suffers. And thus, we are all victims.

Reprints of this article are available. See page 234.

OL

40

SS

8

4

2

JE

992

MI