

# health secrets of your family tree

**M**Y HUSBAND AND I were still rejoicing over the birth of our first child when the devastating news reached me: My 41-year-old sister had a rare, aggressive nasal tumor that was fast closing in on her brain.

A sinking feeling of déjà vu came over me. Our father had died young, of colon cancer, at age 57. His brother had died of the same disease at almost the same age. Suddenly, the familial bonds we all shared became a source of fear rather than comfort.

Within a year my sister was dead. Numb from the loss, I shelved my anxieties about the family's health. Three years passed, another baby arrived and the specter of death receded, edged out by new life. Then, last year, just shy of my 44th birthday, I developed skin cancer on the small of my back. Though it was a harmless, garden-variety form of the disease, I was alarmed. Had I inherited a family vulnerability to cancer?

Instead of obsessing about it, I decided to divert my nervous energy into researching my family medical history. The project has turned out to be more time consuming, and more anxiety provoking, than I had anticipated. I haven't always liked what I've found; but I'm glad I took the initiative. The knowledge I've gained could save my life, and it could also help others near and dear to me.

## Starting The Search

I began by making a few phone calls. As I'd known from the start, cancer is



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OWN HEALTH—  
INFORMATION YOU  
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prevalent on my father's side—but just how prevalent came as a shock. In a single afternoon of contacting his relatives, I learned that one aunt had had lung cancer; another, cervical cancer; and a cousin, basal cell carcinoma—the very skin cancer that popped up on my back.

More medical sleuthing turned up additional cancers, all stemming from my paternal grandmother's line, including a few that killed relatives at disturbingly young ages. After I plotted those affected on the family tree, a pattern emerged. Laid out before me was evidence suggesting a “family cancer syndrome,” as geneticists call clusters of cancers that are probably hereditary in origin.

I'm still filling out branches of my family tree. But based on what I've learned so far, I'm now considering genetic testing. The frequency of the disease on my father's side, a doctor has warned me, could indicate a condition known as hereditary non-polyposis colon cancer, or HNPCC. If his suspicion proves correct, I will require more frequent exams by colonoscopy—a powerful tool for catching colorectal cancer in its early stages. Moreover, I'll need to be carefully monitored for cancers of the uterus and ovaries, which are often associated with the syndrome. Genetic testing could tell me whether these steps are wasted effort—or whether they might keep me alive. *(continued)*

## All In The Family

An estimated 5–10 percent of all cancers are now believed to result from inherited mutations, accounting for as many as 122,000 cases each year in the U.S. Heredity also contributes to diabetes, glaucoma, emphysema and Alzheimer's disease, among others.

When it comes to heart disease, family history counts more than anything else. "It's more telling than an elevated cholesterol level, high blood pressure or smoking history," says Helen Hixon, M.S., a genetic counselor in Los Angeles.

## should you be tested?

If you're thinking of undergoing genetic testing, your first step is to consult a genetic counselor. Ask your physician for a referral, or contact the National Society of Genetic Counselors at 610-872-7608 ([www.nsgc.org](http://www.nsgc.org)).

After reviewing your family medical history, a counselor will explore the pros and cons of genetic testing, laying out options and addressing emotional and practical concerns while leaving the final decision up to you.

Many insurance companies will cover the cost of both consultation and testing, which can run from several hundred to several thousand dollars. Testing requires only a blood sample, and DNA results are usually available in two to four weeks.

The widespread fear that insurers or employers might use genetic results to discriminate against individuals is overblown, in the opinion of most experts. While those concerns were once justified, they say, today individuals' genetic privacy is protected by federal, and often state, law.

Even so, no one should enter genetic testing without careful forethought. While knowing one's genetic status may offer an edge in warding off illness, not everyone who tests positive for a given mutation will develop the disease. What's more, some conditions are difficult or impossible to prevent, or the methods for doing so may be draconian—for example, prophylactic mastectomies in the case of women predisposed to breast cancer.

You're seven times more likely to develop early heart disease if a first-degree relative—a parent, child or sibling—had a heart attack before the age of 65, and more than ten times as likely if the relative's heart attack occurred before age 55.

Some patterns of illness do not become apparent until you plot them on a medical tree, also known as a pedigree or genogram. With that information in hand, you can stay alert to potential symptoms and employ preventative strategies.

These strategies might include changes in diet or exercise routines, or more aggressive medical testing. As part of Cedars-Sinai's new GenRISK Program, for example, patients with a family history of heart disease are screened for high cholesterol, elevated homocysteine levels and raised insulin levels. Depending on the results, the hospital's staff may recommend steps ranging from vitamin therapy to bypass surgery.

In the case of cancer, genetic testing may be in order. The usual reason for such tests: Patients want to quantify their risk before they submit to more extreme preventive measures—intrusive diagnostic exams, for example, or the surgical removal of at-risk organs such as the uterus, ovaries or breasts.

For now, DNA testing for susceptibility to disease is limited largely to family cancer syndromes, with about two dozen tests currently available in this category. Genetic counselors also have tests to identify people likely to develop Huntington's disease, hemochromatosis (an iron overload disorder that, if untreated, can cause organ damage) and a host of rarer conditions.

## Nurturing Your Family Tree

A medical history should, ideally, go back at least three generations, and include your sisters and brothers, parents, grandparents and aunts, uncles and cousins. Next to each name, enter date of birth and, if deceased, the date of death and cause. Then list all the individual's major illnesses, birth defects, neurological or mental disorders, learning disabilities, pregnancy losses and chronic ailments such as migraines or arthritis.

Speak to the family elders—especially the older women, who typically have

**cancer clusters** To spot hereditary cancers, be alert to cases that strike two or more members of a clan at a young age, especially if they fit the profile of these common family syndromes.

|                                     |   |
|-------------------------------------|---|
| <b>BRCA1</b>                        | Breast, ovarian, and possibly colon and prostate  |
| <b>BRCA2</b>                        | Breast (in men as well as women), ovarian, pancreatic and melanoma of the eye   |
| <b>HNPCC</b>                        | Colon, rectal, pancreatic, stomach, endometrial, ovarian and possibly rare brain tumors and skin lesions (sebaceous adenomas) |
| <b>Multiple Endocrine Neoplasia</b> | Thyroid (medullary thyroid carcinoma), adrenal gland and pituitary tumors   |

more intimate knowledge of family health matters. If a family reunion is planned, contact relatives in advance to let them know the particulars you'll need. But be prepared: Not everyone will be enthusiastic about cooperating. "Some people may be afraid that if you start snooping around, you might expose family secrets related to paternity, adoption, suicide and the like," says Karen A. Brooks, M.S., a genetic counselor at the University of South Carolina School of Medicine Department of Ob/Gyn in Columbia. "Be sensitive if you encounter heavy resistance."

In researching my own genogram, I stumbled upon a white lie guarded by my family for more than 20 years: A middle-aged relative's death from "heart failure" turned out to be a euphemism for a harsher truth: a drug overdose.

Disease itself may be a taboo topic among the elderly, leading them to speak in hushed tones about "the Big C," mental illness, and "female troubles" like endometriosis. "If you're told Grandma had stomach cancer, probe further," advises Talia Donenberg, M.S., a genetic counselor in Hollywood, Florida. "What that may really mean is that she had ovarian cancer."

In identifying hereditary dispositions—especially to cancer or heart disease—the age of onset is critical. "Almost every family can point to a lot of heart

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## Heart Healthy

Have you heard that certain fruit juices are supposed to be heart-healthy. Is this true for orange juice?

### Powerful Nutrition

It would be hard to design a better food than orange juice. Citrus juices are naturally fat, cholesterol and sodium free, which makes them perfect for inclusion in a heart-healthy diet. Orange juice was recently ranked as the most nutritious juice, based on the content of 15 vitamins and minerals, when compared to prune, grape, apple, grapefruit and pineapple juices.

Orange juice is an excellent source of vitamin C, an important antioxidant and a vitamin needed to keep blood vessels strong. Orange juice is also a good source of the B vitamin folate. Folate, also known as folic acid, has been shown to decrease risk of cardiovascular disease by decreasing the level of homocysteine in the blood. Additionally, an 8-ounce glass of orange juice contains as much potassium as a medium banana, 450 mg or 13% of the daily value for this key mineral. A diet rich in potassium may reduce the risk of hypertension and stroke.

### Nature's Pharmacy

Much of the recent news about fruit juice has focused on substances called phytochemicals, which literally means "plant chemicals." These substances are found naturally in fruits, nuts, grains, vegetables and tea. Orange juice contains more than 170 phytochemicals and over 60 of them, called flavonoids, function as antioxidants, anti-inflammatory agents and blood clot inhibitors.

One study has shown that orange juice can increase the blood level of HDL, or "good" cholesterol, by 21 percent and lower the ratio of LDL (bad) to HDL cholesterol by 16 percent. Flavonoids are likely responsible for these effects, but there may be other components of citrus fruits that play a role as well.

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**Carla McGill, Ph.D., R.D.**  
Nutrition Sciences  
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## case studies in medical sleuthing

### ELIZABETH KING

The birth of her first child two years ago at age 43 got Elizabeth King to pondering her prospects for a long life. The Chicago businesswoman knew that her family history wasn't encouraging. Early-onset heart disease ran in her father's ancestral line, and strokes were prevalent on her mother's side. King herself suffers from borderline high blood pressure.

Seeking the best preventative care available, King consulted University of Minnesota cardiologist Jay N. Cohn, M.D., a pioneer in cardiovascular risk assessment, who was also treating her brother and sister. "I was a little bit in denial," she said. "But when I saw how all three of us shared a number of markers for heart disease, I got more serious about exercise, yoga and eating the right foods." When she

finishes nursing her baby, King may consider taking blood pressure medication, on Cohn's recommendation. "I may still get heart disease," she concedes. "But I have no intention of making myself an easy target."

### FRANCES HOOGENBOOM

A trip to the family grave plots helped Frances Hoogenboom, a 54-year-old nurse from Lexington, South Carolina, solve a medical mystery. Growing up, Hoogenboom watched one young male relative after another succumb to kidney failure. A family doctor suggested the cause might be Alport Syndrome, a hereditary disease passed down to male offspring by "silent," or unaffected, female carriers.

Hoogenboom tracked down three different grave plots at the church where her mother's ancestors



were buried. Their tombstones strongly supported her doctor's hunch. "It was deeply touching to see how many of the men lived to only eighteen or twenty years of age," she says.

Genetic tests confirmed that Hoogenboom and her two daughters are all carriers. "It's sad that the legacy continues," she remarks, "but nowadays Alport's victims can often live a normal life span with a kidney transplant, so at least it's not the death sentence it once was."

disease among their oldest members," Hixon notes. "But if one or more relatives had any cardiovascular disease in middle age—especially close relatives like a parent or sibling—it definitely raises a red flag."

Memory is frail, so consult actual records whenever possible. The paper trail may lead from birth certificates and school yearbooks to military records, doctors' reports and death certificates. If a family Bible exists, check the opening leaves; it was once common practice for families to jot down information related to baptisms, marriages, deaths and places of burial. Ink fades, but stone endures—so don't underestimate the value of a trip to the family burial plot. You may discover ancestors you never even knew existed, and their longevity is clear from the tombstone dates.

Do you know the hospital where a relative died? If so, the next of kin may be able to retrieve the pathology reports, which can provide such key information as a cancer's site of origin. According to Jill Stopfer, M.S., a genetic counselor at the University of Pennsylvania Cancer Center in Philadelphia, most hospitals keep records 15–20 years, and some large academic medical centers much longer.

### To Test, Or Not To Test?

Who should seek genetic counseling? As a general principle, anyone who has at least two relatives from the same side of the family with the same cancer or serious disease, assuming that two of them are first-degree relatives and at least one of them fell ill before age 50.

Bear in mind these exceptions, however. Many families are peppered with

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cancers or other diseases that may at first glance appear unrelated, but which a specialist recognizes as different manifestations of the same syndrome.

Interpreting genograms can be tricky in other ways, too. Misleading gender stereotypes about disease can obscure patterns that would otherwise be obvious. For example, many people assume that breast cancer can only be inherited from their mother's line. In fact, you shared your father's genes, so pay attention to cases among his sisters, aunts or mother, too. Or they may conclude—again erroneously—that only heart disease on Dad's side is cause for worry.

Another common mistake is to focus only on the side of the family that alarms us the most. Fixated on the many cancers among my father's clan, I only belatedly scrutinized my mother's side, where I did learn something unexpected that could have bearing on my future health. My mother, her sister and their mother all developed thyroid problems between 35 and 65 years of age—a powerful clue that I may be next in line.

## Facing Facts

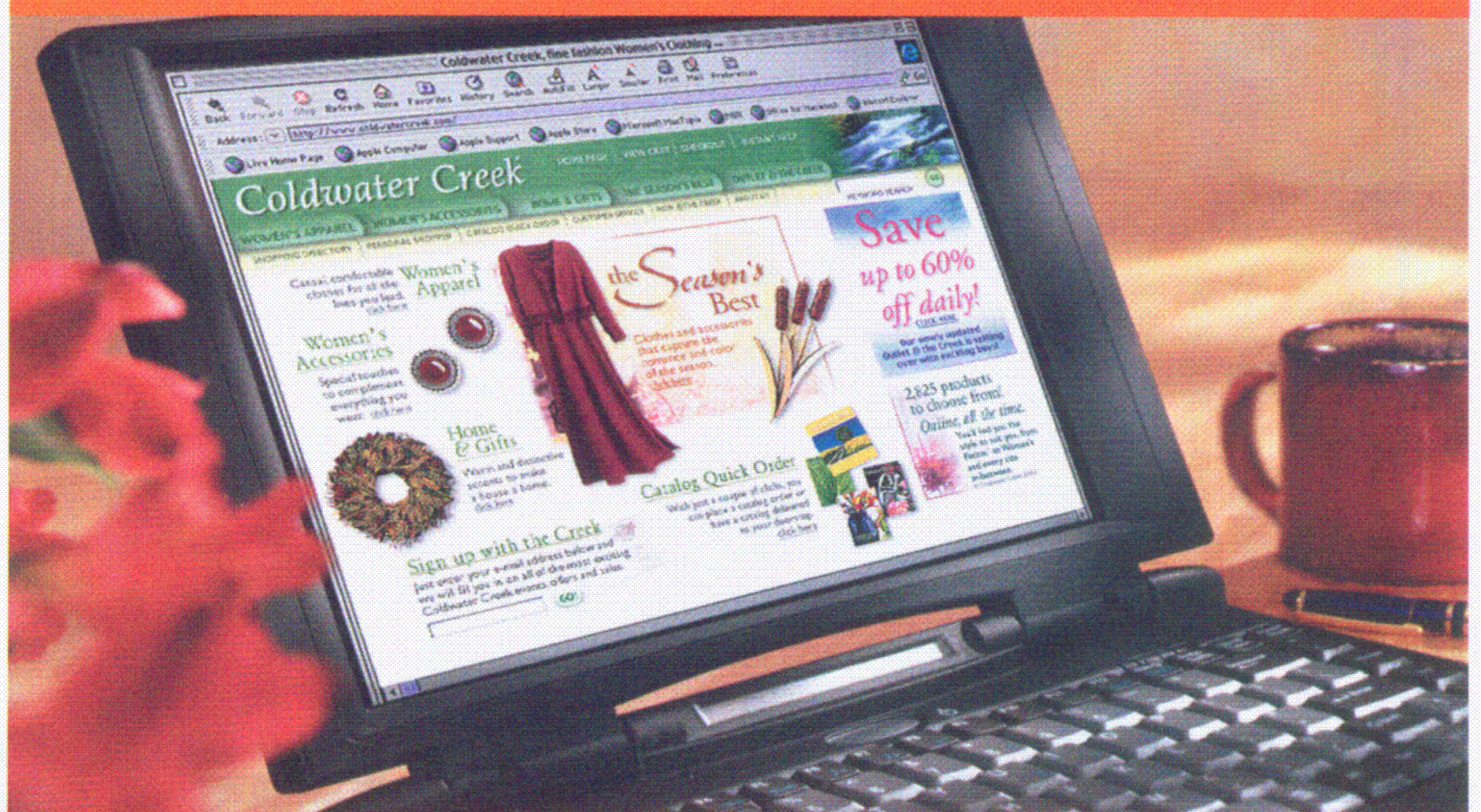
To be sure, knowledge of hereditary weaknesses can be a mixed blessing. Were a test to confirm that I carry a mutation that promotes the growth of cancer, I fear that I might become a world-class hypochondriac. But if, after weighing all the evidence, I'm convinced that testing could improve my chances of staying healthy, I'll probably go for it. Having witnessed the painful last months of my sister's life, I know that an unnecessary trip to the doctor is far from the worst that can happen.

For more tips on tracing your medical roots, including how to track down birth and death certificates, hospital reports, military records and other vital documents, two excellent resources are *Past Imperfect: How Tracing Your Family Medical History Can Save Your Life* by Carol Daus (Santa Monica Press, 1999) and *How Healthy Is Your Family Tree?* by Carol Krause (Fireside Books/Simon & Schuster, 1995). ■

Kathleen McAuliffe is a health writer and **more** contributing editor.

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