special report

dying of embarrassment

DON'T BE SQUEAMISH. DO GET TESTED– AND YOU NEEDN'T BE THE VICTIM OF THE NUMBER TWO CANCER KILLER

BY KATHLEEN McAULIFFE

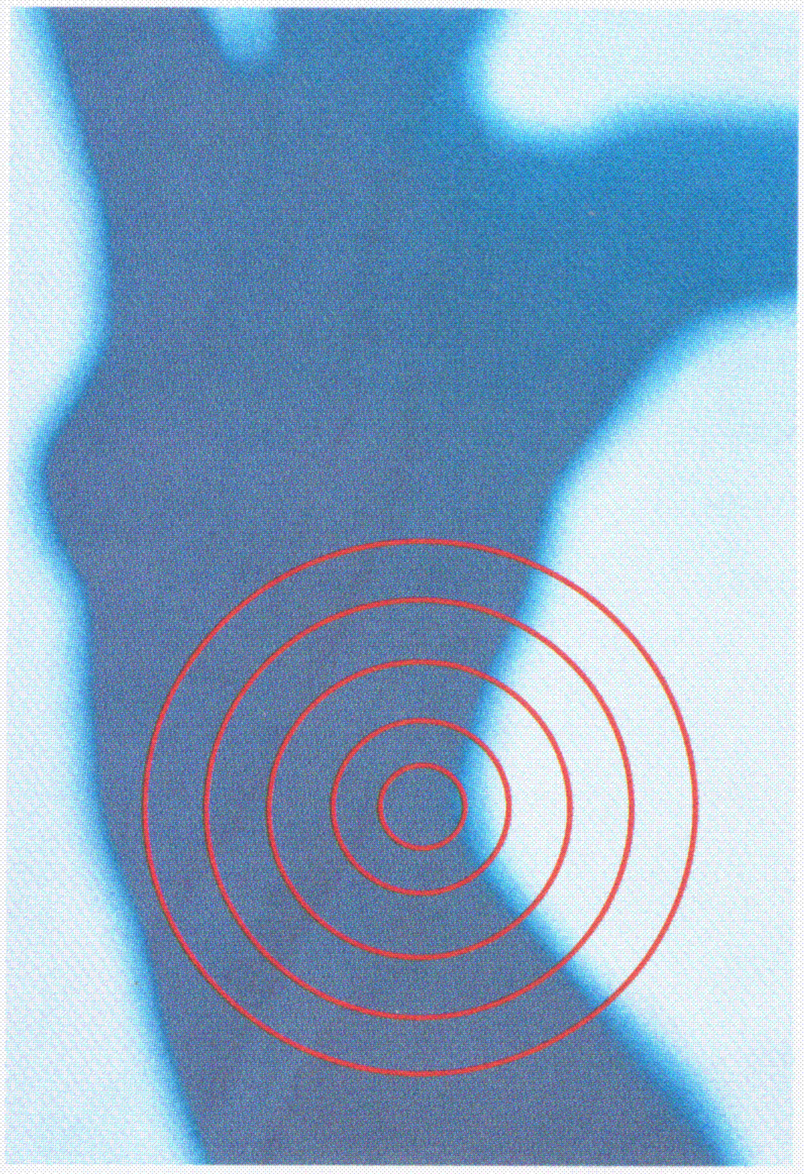
MY FORTIETH BIRTHDAY present to myself was a colorectal exam. Having a three-foot-long tube snaked up my innards was not exactly how I fantasized marking the milestone. But as I saw it, no gift could offer me greater peace of mind or a better shot at living another forty years.

Two decades ago, my father died of colon cancer at age fifty-seven. He had a shock of shiny jet-black hair, a heart as strong as an ox's and a ribald wit. Had his disease been caught in time, he might still be with us now, bouncing his grandchildren on his lap.

Our family's tragedy is repeated every day. Last year, Katie Couric's husband, the TV legal analyst Jay Monahan, lost his life to colon cancer at just forty-two. Six years ago, Audrey Hepburn succumbed to it at sixty-four. Today, baseball players Eric Davis and Darryl Strawberry, both in their thirties, are battling the disease. All told, about 56,500 people die each year from colon cancer. Only lung cancer claims more lives in both men and women.

"Many people think colon cancer is a man's disease, but that's a fallacy," warns Gloria Petersen, Ph.D., a genetic epidemiologist at Johns Hopkins University School of Public Health in Baltimore. In fact, the disease kills slightly more women than men.

People like me, with a relative who died of colon cancer, are three times as likely to develop the disease, often at a young age. But no one should consider herself immune. Seventy-five percent



Colon cancer does target us: It kills slightly more women than men

of cases occur in people without any known risk factor. More than 130,000 new cases will be diagnosed this year, at an average age of sixty-six.

Those dismal statistics enrage experts. "This is one cancer that no one needs to get," says Ernestine Hambrick, M.D., a Chicago-based colorectal surgeon who founded the nonprofit Stop Colon/Rectal Cancer Foundation.

STOPPING CANCER COLD

Imagine a form of mammography that could detect breast cells about to turn cancerous and eliminate them right then and there. Women would be lining up for the procedure, right?

That technology exists for colorectal cancer. Virtually all colorectal cancers begin as small, budlike growths in the intestinal lining, which are known as polyps, and can take ten years to evolve into cancer. "That gives us an extraordinary window of opportunity to intervene," explains Sidney J. Winawer, M.D., head of the World Health Organization Center for Prevention of Colorectal Cancer at Memorial Sloan-Kettering Cancer Center in New York City. Indeed, his own research, published in the December 30, 1993, issue of *The New England Journal of Medicine*, demonstrates that polyp removal decreases the incidence of colorectal cancer by as much as 90 percent. "It's probably the most powerful preventive strategy for cancer that we have," says Winawer.

Findings like these have led to a major overhaul of screening guidelines in recent years. Since 1997, the American Cancer Society (ACS) has recommended that everyone begin colorectal examinations at age fifty, and a decade or more earlier if they have a family history of the disease, or other cancers (especially ovarian, uterine or stomach cancers) or polyps.

Also at dramatically elevated risk are people with a *(continued on page 58)*

PHOTO, DAVID STEWART/TONY STONE IMAGES.

colon cancer

(continued from page 52)

history of inflammatory bowel disorders such as ulcerative colitis or Crohn's disease. Such individuals should consult their doctors about an appropriate schedule of colon checkups.

OUT-OF-DATE DOCTORS

Women, especially, are missing out on colon-cancer screening. Research shows that 43 percent of men have had a colorectal exam, in comparison to just 33 percent of women. The disease's male image, experts believe, is the main reason for that disparity. Women aren't asking about being tested and doctors aren't always recommending it, reports Joanne Donovan, M.D., chief of gastroenterology at Brockton/West Roxbury Veterans Administration Medical Center in Boston. "Anecdotally," says Donovan, "women are telling me their family physicians recommended colorectal screening for their husbands but not for them."

Squeamishness about discussing bowels and the intestinal tract may also stop patients from raising the issue with their doctors. But perhaps the single greatest barrier to testing is fear. "People have the attitude that these are yucky, horrible tests," says Donovan. In one telling survey, conducted in 1995, respondents said they would rather forfeit one to three months of their life than have their colon inspected with a probe. Patients who had actually experienced the procedure, however, said that they would much rather be screened than give up a single day of their life.

Such negative preconceptions lead many people to put off testing until symptoms occur—by which time it's often too late. Signs of the disease include rectal bleeding, bloating, queasiness and persistent bowel changes such as wormlike stool, diarrhea or constipation. But polyps and early-stage tumors are typically "silent." In fact, the most common "symptom" is no symptom. As a result, only 37 percent of colorectal cancers are discovered at a localized stage, when the disease is readily curable. Largely due to late detection, almost half of all people diagnosed with the disease are dead within ten years.

Clearly, the key to slashing the disease's terrible death toll is early detection of polyps. Medicine's most powerful tool for doing that is a colonoscopy, a test that explores the entire length of the colon using a long, thin fiber-optic tube with a tiny camera that transmits a picture to a video monitor. If a polyp is found, tiny cutting instruments can be deployed from the tip of the tube to painlessly extract the growth. In this way, most patients are spared ever getting the disease. And those whose polyps turn out to be cancerous benefit from swifter treatment.

RIVETING VIEWING

When I tell friends about this lifesaving procedure, the typical response is: "Wonderful! But what does it *feel* like?"

Like many other veterans of a colonoscopy, I found the anticipation worse than the test. The nastiest part was not the test, but the preparation for it.

BETTER TREATMENT

A diagnosis of colon cancer is always frightening, but treatment advances are making the disease easier to live with and increasingly curable. Removal of the cancer has become less invasive. Using a laparoscope, doctors can operate through a few small incisions in the abdomen, limiting scars and recovery time. And no longer does a diagnosis of colon cancer mean having to wear a bag to collect excrement. Owing to better surgical techniques, dreaded colostomies are necessary in fewer than 10 percent of cases.

For people with stage II colon cancer—which has not yet spread to the lymph nodes—a new vaccine still in development, called OncoVAX, shows promise for preventing recurrences after tumors have been surgically removed. (OncoVAX is not yet FDA approved.)

Doctors have also refined the use of chemotherapy and radiation, preventing recurrences and prolonging survival.

Medicine has even made progress in helping those with advanced disease who no longer respond to standard chemotherapy. In 10 to 15 percent of such cases, two new drugs—irinotecan and oxaliplatin—have been shown to shrink tumors.

Still higher hopes are riding on angiogenesis factors, compounds found in the body that can stop blood vessels from forming and therefore may be able to starve tumors of their blood supply. This exciting new approach holds out the promise of enhancing current therapy, possibly bringing cures within the reach of more patients.

The day before the exam, I was ordered to fast (except for clear liquids). I also had to drink a gallon of a prescription agent for flushing out the bowel. Its artificial fruit flavor poorly masked a nauseating metallic taste. (I've since learned of a kinder bowel-cleansing method that entails consuming only eight ounces of unpleasant fluid.) The medicine worked: I soon developed mild cramps and a bad case of the runs. A restless night passed, dominated by trips to the bathroom and disturbing dreams about cattle prods.

Early the next morning, after being hooked up to an I.V. line, I was rolled into the examining room and instructed to turn over on my side. My doctor, gastroenterologist Jose Garrido, M.D., connected my I.V. to a bag containing a potent painkiller and a Valium-like sedative. Within seconds, I was as relaxed as a jellyfish. (People who don't want to be aware during the test can ask their doctor for deeper anesthesia.)

To insert the probe, Garrido inflated my colon with a minimal amount of air. "You'll feel a little crampy and bloated," he warned. I did, but was too mesmerized by the picture on the overhead set to notice. I haven't seen such riveting TV in years. The experience was like something out of the Sixties sci-fi thriller *Fantastic Voyage*—only the body I was journeying through was my own.

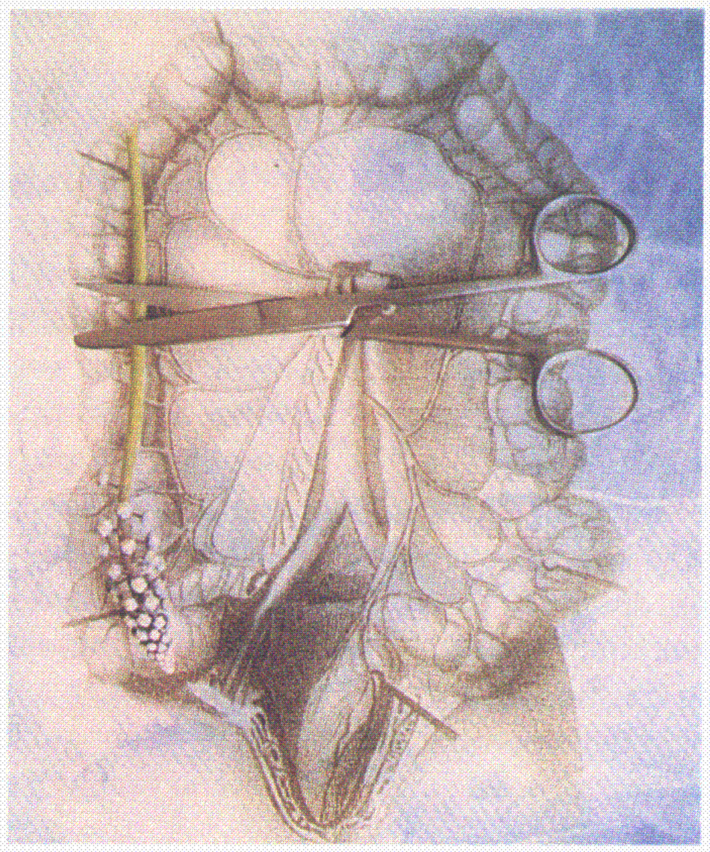
"Is that a polyp?" I asked, noticing a change in the intestinal wall a few minutes into the procedure. "No," Garrido assured me, "that's the opening that leads from the rectum to the left portion of the colon." We gabbed throughout the exam. Before I knew it, twenty

minutes had passed and the procedure was over. The good news belatedly dawned on me: No polyps!

Garrido advised me to come back for another inspection in three to five years. When the disease tends to strike family members at a young age, polyps may evolve more quickly into tumors.

UNFAIR PRACTICES

With mounting proof of colonoscopy's protection against a major killer, doctors are recommending it with increasing frequency. But for now, the bulk of baby boomers are more likely to be screened by flexible sigmoidoscopy (which inspects the lower portion of the colon), combined with a take-home test that looks for blood in the stool. Though easier to perform than a colonoscopy, these twin tests are also less accurate. What your insurance will cover is another matter. "What we're hearing from many patients and doctors is that HMOs and other insurers often restrict coverage of colonoscopies to high-risk patients," reports prevention crusader Hambrick. Harder to justify, some insurers—no one knows how many—are even refusing to pay for the simpler sigmoidoscopy exam that's also recommended by the ACS for people of average risk over fifty. As of January 1998, the over-sixty-five population can at least get that test paid for under Medicare.



Prevent cancer—and surgery—with an early colonoscopy, which nips out polyps

What should people do if their health insurer won't pay for the colorectal screening recommended by their doctor? Launch a formal complaint, advises Hambrick. Even if the policy's administrators don't cave in, the complaint will serve a good purpose. "The more people who protest, the more likely HMOs and other groups will change their practice," she says.

In the meantime, if necessary (and if you can afford it), consider paying for the test out-of-pocket. View it as an investment in your life.

Meanwhile, exciting new developments could revolutionize how both patients and insurers view colorectal screening. One great hope for the future is virtual colonoscopy, a method of exploring the inside of the colon via a CT scan. It's

A GUIDE TO COLORECTAL SCREENING

Regular colorectal examination saves lives. For people of average risk, the American Cancer Society recommends a variety of screening options, beginning at age fifty. (People at high risk should begin screening at forty.) Discuss with your doctor which ones are appropriate for you.

FECAL OCCULT BLOOD TEST (FOBT) The most widely used screening method, FOBT looks for blood hidden in stool. After making minor dietary changes, the patient collects samples from three consecutive bowel movements. If blood is detected, a colonoscopy will be scheduled to check for polyps or cancer.

FOBT may miss polyps and early-stage cancers that are not bleeding. For that reason, doctors recommend combining the test with flexible sigmoidoscopy (right). FOBT can also give false positive results, due to diet, medications or hemorrhoids.

☐ *Cost: $5 to $10. Frequency: Once a year. Effectiveness: A one-time test detects less than 10 percent of small polyps, about 30 to 50 percent of large polyps and 40 to 50 percent of early-stage cancers.*

FLEXIBLE SIGMOIDOSCOPY This test can be performed in a doctor's office with minimal bowel cleansing beforehand—usually via a Fleet enema. It does not require sedation. A fiber-optic tube with a lens and light at the end is used to inspect only the lower third to one-half of the colon. When combined with the FOBT (left), sigmoidoscopy is estimated to reduce colon-cancer deaths by half.

☐ *Cost: $100 to $200. Frequency: Every five years. Effectiveness: Detects 30 to 45 percent of small polyps, and 35 to 50 percent of large polyps and early-stage cancers.*

COLONOSCOPY The most expensive test, it is typically performed in a hospital or office by a trained gastroenterologist, surgeon or family practitioner. Preparation consists of a liquid diet and bowel-cleansing agents twenty-four hours in advance. With the patient under sedation, a fiber-optic tube is snaked through the entire length of the colon. The procedure causes only mild discomfort. A colonoscopy is the most accurate test for finding polyps and cancers. What's more, this method is the only one that allows doctors to remove growths during the procedure. Though widely viewed as very safe, a colonoscopy carries a slight risk of causing bleeding or perforating the colon, or of introducing infection if not done properly.

☐ *Cost: $500 to $1,000. Frequency: Once per decade for average-risk patients and more frequently for high-risk patients. Effectiveness: Detects 85 percent of small polyps, and up to 97 percent of large polyps and early-stage cancers.*

DOUBLE-CONTRAST BARIUM ENEMA This test might be an option for people with certain medical conditions that can make other tests inappropriate. This test also requires preparation with a liquid diet and bowel-cleansing agents. The exam—essentially X rays of the colon—is performed by a radiologist. Liquid barium and air are introduced into the colon to make growths visible on the X-ray film. Although the entire colon can be examined, small cancers and polyps may be missed. If a growth is detected, a colonoscopy must be performed to remove or biopsy it.

☐ *Cost: $300 to $500. Frequency: Every five to ten years. Effectiveness: Detects 50 to 80 percent of small polyps, 70 to 90 percent of large polyps and 55 to 80 percent of early-stage cancers.*

PHOTO, IRAIDA ICAZA.

basically a highly sensitive X ray. Computer imaging techniques then create multidimensional views of the colon without inserting a probe into the rectum. Though still experimental, early data on virtual colonoscopy's accuracy and cost effectiveness are encouraging, and researchers are exploring whether the scan can be done without the usual bowel-cleansing preparation.

PREVENTION, DAY BY DAY

A healthy lifestyle is just as critical as screening when it comes to colon-cancer prevention. Start by boosting exercise and eliminating bad health habits such as smoking and drinking excess alcohol. Other important measures:

- *Dietary changes.* Doctors recommend curbing consumption of red meat and other sources of dietary fat while limiting total caloric intake to maintain a normal body weight.
- *Fiber:* Numerous studies have shown the benefit of a high-fiber diet in preventing colon cancer. However, in a surprising turn, results from the large-scale Nurses Health Study, released in January, showed no benefit. The fiber issue is now controversial, and researchers are calling for more studies. "Still, many experts continue to recommend 25 to 30 grams of fiber a day, which may be good not only for the colon but for the heart and health in general," says Moshe Shike, M.D., director of Memorial Sloan-Kettering Cancer Prevention and Wellness Program.
- *Folic acid.* Some epidemiological studies suggest that this B vitamin, particularly when taken as a supplement, lowers the risk of colon cancer.
- *Calcium.* This mineral helps to soak up fecal bile acids suspected of promoting tumors of the digestive tract.
- *Aspirin.* Most epidemiological studies suggest an aspirin a day cuts the risk of digestive tumors by 30 to 50 percent. But because aspirin can cause bleeding, don't take daily doses without consulting a health-care professional.
- *Hormone-replacement therapy (HRT).* Several large studies of postmenopausal women have shown that HRT may help to reduce colorectal cancer, though this conclusion is controversial and far from proved. And since HRT can increase a woman's risk of breast cancer, consult your doctor. ■

Kathleen McAuliffe has just scheduled her second colonoscopy.

WHEN CANCER RUNS IN FAMILIES

In recent years, researchers have identified several genes associated with colon cancer. Susceptibility tests are now available for Hereditary Non-Polyposis Colorectal Cancer (HNPCC), a newly defined genetic syndrome in which multiple generations of a family are stricken by colorectal cancer at a typical age of forty-five. Cancers of the uterus, ovaries, ureter, pancreas and stomach may also figure prominently in families with this syndrome. The HNPCC mutation accounts for 5 percent of all cases of colorectal cancer, making it among the most common inherited causes of the disease.

A more recently discovered mutation linked to colorectal cancer occurs in about 6 percent of Ashkenazi Jews (of Eastern European descent) but is extremely rare in the non-Jewish population.

Familial Adenomatous Polyposis (FAP), a condition marked by hundreds of polyps in the colon, has been traced to a different kind of rare mutation in the same gene, responsible for less than 1 percent of all colorectal cancers.

Why have a genetic test? Individuals who know they have a mutation might be more likely to follow screening guidelines and adopt a healthier diet and lifestyle. Women with the HNPCC mutation should also be intensively monitored for reproductive cancers. People who learn that they have been spared the family gene for colon cancer often feel tremendous relief, but may slack off on screening—a serious hazard given that the majority of colon cancers arise from sporadic mutations.

For now, I've decided to forgo gene testing, but I do plan to see a genetic counselor to explore the option more closely. Almost all major medical centers now offer this service to individuals with a strong family history of the disease.