Two doctors told Tonia Barringer that she didn't have cancer—but she did

THE CANCER DOCTORS STILL MISS

When your doctor tells you a mole is harmless, should you believe him? Not necessarily. Melanoma often goes undiagnosed, even by the experts. By Kathleen McAuliffe

"I've got melanoma," my friend Tonia Barringer, then thirty-one and living in Miami, Florida, blurted over the phone. "Do you remember that mole on my ankle?"

I remembered it well. She had pointed it out to me a few months before because it had started to bleed while she was toweling her leg dry after a shower. A lifelong sailor with red hair, blue eyes and ultra-fair skin, Tonia was well aware that she was a prime candidate for skin cancer and had gone immediately to be examined. But two dermatologists had reassured her that the mole was harmless. "You probably rubbed it or scraped it with your shoe," she was told. Neither specialist had been concerned enough to biopsy it.

Almost two months later, the mole swelled into a ugly red bump the size of a lima bean. Tonia marched off to a third dermatologist and politely but firmly insisted that the mole be removed. The doctor agreed it looked suspicious.

The visible part of the mole turned out to be just one of the cancer's tentacles.

The worst part, Tonia later confided, was when the doctor took out a black marker and drew a circle as big as a lemon indicating the chunk of flesh that he'd have to remove to minimize the risk of leaving behind any cancer cells. "That's when it really hit home," Tonia said. "I thought I was going to throw up."

Now, more than five years later, Tonia remains cancer-free. The first year after her diagnosis, her oncologist told her there was about an 80 percent chance that a cell sloughed off from the original site would crop up someplace else in her body as a new tumor. Such metastasized melanomas typically strike the liver or the lungs and are a virtual death sentence. Today, her risk of such a recurrence has dropped to under 20 percent, according to her doctor.

Ever since my friend's experience, I've had an abiding paranoia about even the tiniest freckle (though dark-eyed, I too have very fair skin and live in Miami). So when a large mole on my back recently started to feel itchy, I resolved to see the best melanoma expert I could find in the area.

Getting checked

Recommendations from several doctors led me to Robert Johr, M.D., the fifty-year-old director of the Pigmented Lesion Clinic (essentially a mole surveillance unit) at the University of Miami School of Medicine. By the time my appointment with him rolled around a week later, the mole had stopped itching. What's more, I'd started to suspect the culprit was a new bra. "I'm afraid I may have overreacted," I told Johr.

He was quick to reassure me. "There's an epidemic of melanoma," he said. "I wish more people reacted like you." If caught early, it is one of the most curable cancers. But too often it is found late. As Johr warned, "A single millimeter of growth down into the skin can mean the difference between life and death."

As I sat naked under bright lights, Johr began examining me, his gaze fixing first on the mole that had prompted my visit. "Nothing to worry about here," he pronounced with confidence. For the next ten minutes, Johr probed my scalp, behind my ears, under my arms, even between my toes. Occasionally, he'd stop to scrutinize a spot more closely with an instrument called a dermatoscope.

To my surprise, Johr zeroed in on a mole on the underside *(continued)*

of my right breast. It was larger and darker than any of the other moles on my chest, and its borders had an irregular shape. Had it not been directly out of my line of vision, I probably would have obsessed about it. "This is okay, but it's the type that worries me," Johr informed me, zooming in for a second look. "How long has this been here?" I told him I had never noticed it before. To be safe, Johr advised me to keep a close eye on it and to come back within a year to be rechecked.

No sooner had I gotten dressed than I began to regret not having asked for it to be biopsied. After all, Tonia had been reassured twice. I shared her story with Johr.

He told me that technological advances in diagnosing melanoma are taking some of the guesswork out of when to biopsy. A major boon for patients with suspicious skin lesions is the emergence of computerized systems for imaging and tracking moles over time. Another helpful tool, now employed by 10 to 15 percent of specialists in the U.S., is the dermatoscope Johr used. Essentially a fancy magnifying glass, it eliminates light reflected from the surface of moles and other pigmented areas, enabling the underlying structure to be seen in greater detail. Studies have shown that dermatologists adept at using this instrument are at least 10 percent more accurate in diagnosing melanoma than those relying on the unaided eye. Because of his expertise with the dermatoscope, Johr was confident my mole did not merit closer examination. While a biopsy is just a minor surgical procedure, it does leave a scar. If I didn't need one, I was happy to skip it.

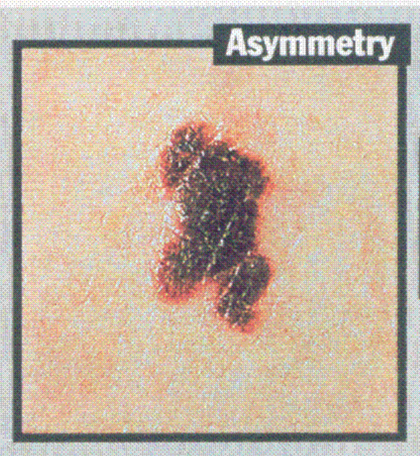
There are no ironclad rules about when a biopsy is necessary. But the experts themselves say a doctor in doubt should cut it out. "If you have a gut feeling that something is wrong with a mole, let the doctor know and request a biopsy," advises June K. Robinson, M.D., a professor of medicine at Loyola University, in Chicago. If you continue to feel concerned, consider seeing a second specialist, or even a third. Tonia may be alive today because she did just that.

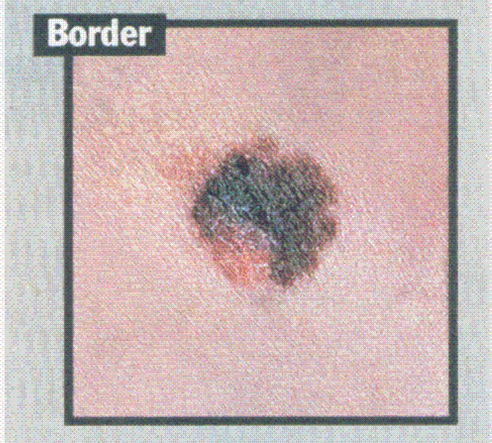
Melanoma update

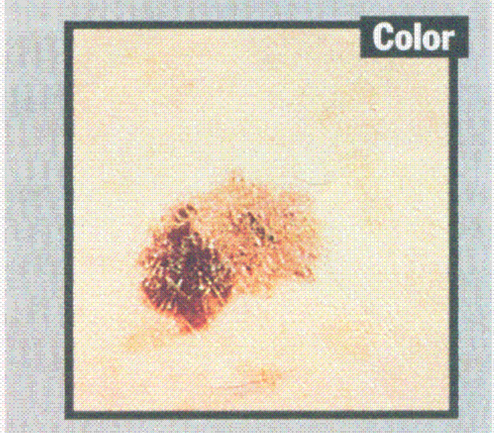
What I learned about melanoma from Johr, and later from other specialists, was enlightening. Half of all new cancers are skin cancers. The two most common types are basal-cell carcinoma and squamous-cell carcinoma. Although common, they are usually caught early and treated successfully.

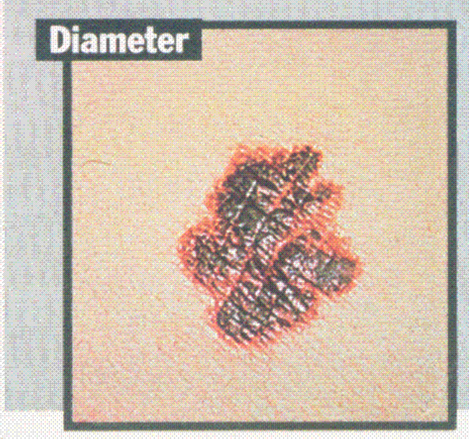
Melanoma is rarer and by far the deadliest. Often striking at an early age, melanoma is more common than any non-skin cancer among people between twenty-five and twenty-nine years old. Johr wasn't exaggerating when he used the word *epidemic.* In 1935, melanoma struck about one in fifteen hundred people. Today, it strikes one in eighty-two.

Although the destruction of the ozone layer is often blamed for the surge in melanoma, dermatologists are just as inclined to fault changing customs—notably, the glorification of a tan, the fashion of wearing scant clothing for outdoor recreation and intense intermittent exposure to sun, as office workers sunbathe on weekends or take vacations in equatorial climes. Though seldom appreciated, melanoma occurs more often in people exposed to bursts of sunlight than in those who are consistently in *(continued)*









SKIN CHECK

According to The Skin Cancer Foundation, to thoroughly examine your skin for suspicious spots, it's best to request the help of a family member or friend. Be sure to check all parts of the body, including the toes and soles of the feet, behind the ears and the scalp (use a mirror and blow-dryer on a cool setting to blow hair out of the way and expose each section).

Melanoma can be signaled by virtually any change in a mole or a brownish spot such as a freckle or birthmark. Watch for the following ABCD warning signs:

- **ASYMMETRY: A mole that is uneven, such as one that is higher in some spots than others.**
- **BORDER: Any change in the borders of a mole, especially irregular, notched or scalloped edges.**
- **COLOR: Uneven color, such as multiple shades of brown or a speckled pattern of red, white and blue.**
- **DIAMETER: Moles larger than the head of a pencil eraser or any change in size or a new dark spot after age twenty-one.**

In addition, watch for changes in the surrounding skin such as redness, swelling or colored blemishes near the pigmented area, scaliness, oozing, crusting, ulceration or bleeding.

Basal-cell and squamous-cell carcinoma, the two most common skin cancers, are typically found on sun-exposed parts of the body such as the face, ears, shoulders, scalp and back. Warning signs include:

- **A persistent red patch or open sore that may be crusty, scaly, bleeding, itchy or oozing.**
- **A wart-like growth that may crust or bleed.**
- **A shiny bump that's often pearly, pink or red, but may be brown or black in dark-haired people.**
- **A smooth or elevated growth with a depression in the center.**
- **A scar-like area that is white, yellow or waxy.**

PHOTOS, COURTESY OF THE AMERICAN ACADEMY OF DERMATOLOGY

the sun. (However, basal-cell and squamous-cell tumors are linked to one's total amount of sun exposure.)

Genetics are also of paramount importance: Fair skin that burns quickly and a family history of melanoma are thought to increase a person's risk sixfold. (After Tonia's diagnosis, her uncle developed melanoma in the same place.) Other risk factors include many moles or freckles, multiple sunburns in childhood and having red or blond hair.

Know thy body

To detect skin cancer early, self-examination is critical. Dermatologists say they would be more likely to biopsy a mole that looked normal to them if someone diligent about surveying her body reported that it had changed in any way. Yet in a survey of one thousand adults commissioned last year by the American Academy of Dermatology, fewer than half of the respondents had ever conducted a self-examination and only 26 percent knew the warning signs (see "Skin Check," page 54).

Self-examination takes on even greater importance when the diagnostic limitations of doctors are taken into consideration. Studies suggest that general practitioners accurately diagnose melanoma only about 40 to 50 percent of the time. Dermatologists do better, typically finding about 75 percent of melanomas. But as Tonia's case and these statistics illustrate, even specialists are not infallible. Certain melanomas are smooth and clear and fool almost everyone; diagnosing them can tax the best of clinicians. So it helps tremendously when a patient can provide historical information about a mole.

Even dermatologists aren't doing full-body exams—most just check a leg or back on a complaint-by-complaint basis, which further reduces the chance of finding melanomas early. And, warns Johr, "Most of the time I find melanoma on a part of the body where the patient hadn't a clue there was anything wrong." The bottom line: Know your own body, ask about spots that worry you and insist on a full-body exam.

Staying safe

To prevent all types of skin cancer, limit your exposure to the sun. When outdoors, wear a wide-brimmed hat, sunglasses and protective clothing (ideally made out of heavy, tightly woven fabric), and lather on the sunblock. Doctors recommend using a product with a sun protection factor (SPF) of 15 or higher that screens against ultraviolet type A and type B (UVA and UVB) radiation.

Until quite recently, sunblocks offered only partial protection against UVA. UVB radiation causes sunburn and is most strongly linked to non-melanoma skin cancers. The latest products offer the same shield against the entire UVA spectrum. UVA penetrates to deeper layers of the skin—and new research indicates it may play a key role in melanoma, wrinkling and sagging skin. Among the best UVA blocking agents are Parsol 1789 and micronized titanium dioxide. Other potent UVA filters include octylcrylene, cinnamates and benzophenones.

But remember, lotions are not an invincible shield against the sun's damaging rays. In fact, they may do more harm than good if you use them to stay out in the sun longer than you would otherwise (without sunblock, burning skin would force you indoors). Increased exposure may even explain why some studies show an increased incidence of skin cancer among sunblock users. (Other studies show a protective effect or no effect.) According to epidemiologist Marianne Berwick, Ph.D., of Memorial Sloan-Kettering Cancer Center, in New York City, whose research on this issue made recent headlines, her findings do not mean sunblock is useless or dangerous in itself—as readers of some accounts might have concluded. "Use it," Berwick urges, "but recognize its limitations." There is no substitute for staying out of the sun—particularly between the hours of ten and four, when the rays are most intense.

Hope on the horizon

Today, melanoma is one of the deadliest malignancies, but doctors are making strides in treating it. Among the most exciting developments are tumor vaccines for patients with advanced melanomas. The vaccines were built on an intriguing medical observation: Sometimes a cancer spontaneously disappears. Researchers believe the patient's immune system may have attacked it. Vaccines, usually made from melanoma cells modified to be harmless, seek to stimulate and enhance this natural response. Though far from perfect, such treatments are already achieving good results for a small number *(continued on page 60)*

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of patients in clinical trials, ranging from a modest shrinkage in the tumor mass to total eradication. Thanks to progress in the field, highly effective melanoma vaccines could become widely available in as little as five years, predicts Craig Slingluff, M.D., chief of surgical oncology at the University of Virginia School of Medicine, in Charlottesville.

Another new technique that is helping patients is sentinel lymph-node biopsy. Because melanoma frequently spreads to the rest of the body via the lymph system, doctors often remove all lymph nodes near the primary site of the tumor as a routine precaution. With this new biopsy, however, they can determine if the cancer has actually spread to the lymph system, thereby reducing unnecessary surgeries. The technique entails injecting a dye near the melanoma. The dye is carried by the lymph system to the node first in line from the tumor. Once marked, this so-called "sentinel" node is extracted through a small incision, using just local anesthesia. If the sentinel node is cancer-free, the remaining nodes are usually unaffected.

The cancer of the young

About one third of women diagnosed with melanoma are of childbearing age. According to Johr, medical views have swung back and forth for decades on whether the hormones of pregnancy might reactivate dormant melanoma cells. But the latest evidence suggests that pregnancy probably won't trigger a recurrence. Should a woman develop a melanoma during pregnancy, however, aggressive treatment of her disease could harm or kill her fetus. The added strain of being pregnant while seriously ill could also endanger her own life. Because most recurrences happen within three years of the initial diagnosis, many doctors counsel such women to wait before trying to conceive a child.

Although Tonia still feels as if the sword of Damocles is dangling over her head, she and her husband ultimately decided to wait only two years after her diagnosis before attempting to start a family. "It wasn't an entirely rational choice," she explains. "We just wanted kids so badly." Now thirty-seven, she is the glowing (though extremely pale) mother of eighteen-month-old twin boys and has long since fled Miami's scorching sun for a cooler Connecticut climate.

As for me, I'm still living in Miami. And I'm no longer fretting about that worrisome mole. When I showed it to my husband, he was unimpressed. "That's been there as long as I've known you," he insisted. "It's always had that funny diamond shape."

Never again will I accuse him of being unobservant. ●

Kathleen McAuliffe has written for The Atlantic Monthly and The New York Times.