

# From Health Scare to Transformative Change

“I’m so impressed by the brilliance and dedication of the researchers and doctors working in this field,” says MRA co-founder Debra Black. “Together we are cracking the code.”

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By Cody R. Barnett, MRA Director of Communications

Every three months, at her regular full-body exam, Debra Black’s dermatologist — the head of dermatology at a top institution — kept saying the small spot on the bottom of her foot was nothing of concern. “It’s just a wart or maybe a ganglia,” she recalls being told.

Four years later, the diagnosis still didn’t feel right. She knew that she was at higher risk for skin cancer because she’d been diagnosed with [melanoma in situ](#) eight years earlier which was why she was so diligent about skin checks. It never occurred to her to question her doctor.

Thankfully, a friend recommended her podiatrist. After about 30 seconds, the doctor turned to her and said, “I’ve been doing this for 30 years, and no way is this a wart.” A 3D sonogram confirmed his suspicions, and the diagnosis was confirmed as late, Stage 2 acral melanoma.

“It was a horrifying time. Despite seeing a dermatologist every three months, he completely missed it,” recounts Debra. “You can’t just blindly accept what your doctor says. It’s easy to be relieved about good news — and 99% of the time that’s right — but not always. I encourage people to ask questions. You know your body.”

Treatment was hard. “I had [stage II](#), with a thick and ulcerated lesion, which is everything you don’t want.” First, the tumor was removed. Next, she needed two skin grafts that required her to keep her foot elevated above the rest of her body for 23 hours a day. She was confined to a wheelchair, then a walker, and today she still isn’t able to go for long walks like she once did. “I feel very lucky to be alive.”

With her own treatment behind her, she and her husband Leon researched more about melanoma. They quickly learned that melanoma isn’t ‘just skin cancer’ and that at the time only about 17% of people diagnosed with stage 4 disease survived five years.<sup>1</sup>

Mike Milken, a close friend, confided that he too had been impacted by melanoma when his own father died due to the disease some 40 years previous. They were all shocked to learn the

treatment landscape hadn't really changed since then. Mike challenged Debra and Leon to do for melanoma what he did for prostate cancer and change the landscape for patients facing the disease.

That's exactly what they did in 2007 when they founded the Melanoma Research Alliance under the auspices of the Milken Institute with an initial \$25 million commitment. Debra explains, "we wanted cures and better treatments and decided that funding research was the best way to fast forward opportunities for patients."

From the beginning, Debra and Leon knew they couldn't do it themselves and embedded the spirit of cooperation deep into MRA's DNA. From the annual scientific retreat, which brings together hundreds of the brightest minds in melanoma to creative partnerships with like-minded brands such as L'Oréal Paris, the focus on building bridges is both deliberate and clear. "Everyone brings something to the table, and we are eager to work with all stakeholders."

Since then, MRA has directly invested more than \$101 million in cutting-edge melanoma research world-wide and has leveraged an additional \$101 million from other sources. MRA-funded research has directly touched all newly approved therapies and has jumpstarted the early-career research pipeline for researchers entering the field.

For patients, the field could not look more different than it did then. Someone newly diagnosed with late-stage melanoma has access to 12 new FDA approved treatments — an explosion in progress almost unheard of in oncology. And while these advances aren't helping everyone yet, they represent significant progress. In fact, lessons learned first in melanoma are rippling out to other cancers.

Debra continues to serve as the chair of the MRA [Board of Directors](#) and is steadfast in her commitment to both MRA and its mission. "In the beginning, I didn't know how much melanoma would permeate my life." In her role as chair, she supports the professional staff, builds bridges and makes introductions, and encourages all stakeholders to be actively engaged.

Her family is following her lead. In addition to herself, her husband [Leon](#), oldest son [Ben](#), brother [Richard Ressler](#), and sister-in-law [Jami Gertz](#) all serve on MRA's Board of Directors. "My family is very supportive in every way, and I'm lucky that they are so engaged," says Debra.

In ten years, Debra and Leon have contributed over \$50 million to MRA. They also underwrite all staffing, development, and administrative fees because, "It's very important to us that when people donate, they know their donation goes directly to research."

When talking with people about melanoma, Debra does not hold back: "People need to know that melanoma is serious. You cannot just shrug it off. Check yourself and your loved ones, and if you see something get it checked by a professional."

For people recently diagnosed with melanoma, her advice depends on the stage: "If early, I suggest that people be vigilant and get two opinions. I also reassure them that they will be

absolutely fine,” says Debra. However, for those diagnosed with later stage melanoma, “unfortunately, the outlook is so much more complicated. I connect them to MRA staff and we try to help them find and locate the best treatments for their specific melanoma.”

Debra is proud of what MRA has done, but she also knows that it isn’t enough. It is estimated that almost 300,000 people will be diagnosed with melanoma globally this year, and every day we lose people to this disease.

“This work is thrilling. I’m so impressed by the brilliance and dedication of the researchers and doctors who work in this field,” says Debra. “We’re eager to support them and to help educate others about the importance of this work. Together we are cracking the code and have made some real progress that’s making a difference to patients and families.”

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