Living Life After

BY KIM IRWIN  PHOTOGRAPHY BY JOHN LICHTWARDT
Brad Zebrack beat Hodgkin’s lymphoma 20 years ago but he’s never felt that the cancer ever really left him.

It took a year after he finished treatment to shake the fatigue that gripped him and kept him from enjoying everyday activities like hiking or riding a bike. Five years after his diagnosis, cancer again invaded his life when Zebrack learned that his treatments had left him sterile and unable to father a child. Even now, a simple cold or cough carries with it the fear of a relapse.

Since the moment of his diagnosis, “cancer has always been a part of who I am,” the 45-year-old Los Angeles man says. “It’s there in my head. But I try to push it into the back of my mind.”

Santa Monica teen-ager Victoria Miranda was just 14 years old when she was diagnosed with a form of childhood sarcoma that developed in the front portion of her brain. She underwent a year of chemotherapy and radiation, had surgery to remove what was left of the tumor, then received more chemotherapy.

Like Zebrack, she is a survivor. Her cancer is gone now, but it has left an indelible stain. Miranda’s legs are weak and she does not walk with a normal gait — she often is unsteady and feels off balance. She gets severe headaches and has pain in her hips. Her doctors say she’ll be on thyroid medication for the rest of her life.

“Once you’ve been through cancer, your whole life changes,” says Miranda, now 17, who graduated from Santa Monica High School in June. “It is something you have to deal with your entire life.”

Oncologists traditionally have focused on successfully treating cancers like Zebrack’s and Miranda’s and ensuring that the disease does not return. However, once that goal is reached, lapses in communication can occur. Many patients return to their primary-care physicians without knowing what follow-up tests they should have, when and how to monitor for recurrence or what physical and emotional problems they might experience months, and even decades, later as a consequence of their treatment.

A new program at UCLA’s Jonsson Comprehensive Cancer Center aims to bridge these gaps by focusing on the needs of the increasing number of survivors living post-cancer in the United States. The Lance Armstrong Foundation (LAF) has named UCLA a Livestrong Survivorship Center of Excellence, and provided the university with a five-year, $1.7-million grant. The grant established the UCLA-Livestrong Cancer Survivorship Center of Excellence.

UCLA and four other centers across the country make up the Livestrong Survivorship Center of Excellence Network, an invitation-only partnership among the LAF and selected National Cancer Institute (NCI) comprehensive cancer centers. The centers, along with their community affiliates, will conduct critical survivorship research, develop new interventions to improve the coordination of care for survivors and work to establish new models of care delivery within the community.

Dr. Patricia Ganz, director of cancer-prevention-and-control research at UCLA’s Jonsson Comprehensive Cancer Center, heads up the UCLA-Livestrong Cancer Survivorship Center of Excellence. The target audience for the centers is

For survivors, cancer and its aftermath forever remain a part of their lives.
huge — more than 10 million Americans today are survivors of cancer, a group that is larger than the population of New York City and represents about 3.3 percent of the U.S. population.

“Most cancer survivors are cared for in the community by community physicians,” Dr. Ganz says. “Oncologists often lose touch with their patients when they finish treatment, yet vital issues may need to be addressed. Up until now, we’ve had poor coordination at the end of treatment, and poor communication with the patient about their future medical needs.”

The move to meet the needs of survivors represents a welcome change of direction in cancer research and treatment, says Dr. Julia Rowland, director of the National Cancer Institute’s Office of Cancer Survivorship.

“It wasn’t until about a decade ago that most people began to look seriously at survivorship and develop an evidence base to support new programs,” Dr. Rowland says. “No treatment for cancer is benign — they all have consequences. We have to talk to survivors about what problems they might face.”

In the 1970s, about 50 percent of cancer patients survived five years. Today, that number has increased to 66 percent. About 14 percent of the 10 million-plus cancer survivors alive today were diagnosed more than 20 years ago. While they may have survived their disease, the ripples — physical, emotional and social — can be felt throughout their lifetimes. Late effects can show up 20 or more years after treatment, says Dr. Jacqueline Casillas, a pediatric oncologist and associate director of the survivorship center. The impact of these late affects can vary, depending on the age of diagnosis, exposure to chemotherapy and radiation — the doses and parts of the body exposed — and the intensity of the therapy, as well as the severity of the cancer itself.

Survivors of childhood cancer, for example, may later experience learning disabilities, cardiac problems, and growth and fertility issues. Psychological dysfunction and second malignancies are not uncommon. For those who survived cancer as adults, a host of other issues may await them. Patients who receive radiation and hormonal treatments may later suffer premature osteoporosis. Men who have survived prostate cancer may have a loss of libido and erectile dysfunction. Women who were given the drug Herceptin to treat breast cancer may, in some cases, have an increased risk of heart damage. Survivors of breast cancer

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also may suffer with fatigue, depression and sexual dysfunction.

Part of the survivorship center’s mission, then, is, through scientific research, to determine what physical and emotional problems survivors will face, and whether those problems vary according to cancer type.

“By setting up these centers, we’ll have an opportunity to evaluate different models and determine, with scientific-based evidence, what care and services need to be provided,” Dr. Rowland says. “This also sends an important message to survivors that their health going forward is important to us. I think we’ll find that cancer patients will feel less abandoned, have more dialogue with their physicians and feel more empowered.”

None recognize the need for greater service to this vast population better than the survivors themselves. “Cancer and its treatment have physical, emotional and social effects that last long after therapy is completed,” says Zebrack. “It’s great that medicine has gotten so good at treating cancer, but because of that success, a lot of people out there must deal with other important issues as well. They need help.”

*Actor and screenwriter Jon Kasdan was 17 when he was diagnosed with Hodgkin’s lymphoma a decade ago. He got through the treatment, but says he continues to suffer from emotional late effects.

“For me, the hardest part of the whole experience was the anxiety,” says Kasdan, who wrote and directed an upcoming movie for Warner Bros. that stars Meg Ryan as a breast-cancer survivor — a story that sprang, in part, from his own battle with the disease.

“I hope my experience left me with a deeper appreciation for life,” says Kasdan. “But I’m more limited now in terms of the boldness with which I live my life, and I wish that weren’t so. Sometimes I feel like it’s more difficult for me to do simple things, like commit to a relationship.”

The Jonsson Comprehensive Cancer Center has a rich history of focusing on survivorship and helping people like Kasdan to manage the attendant issues. The recently established Life
After Cancer Clinic helps childhood-cancer survivors deal with their late effects. The 10-year-old Patients and Survivors Program conducts prevention and control research on behavioral interventions, assessment of quality of life, nutritional intervention and symptom control.

Now, with the LAF grant, the new center will be able to do even more, providing cancer survivors and their primary-care physicians with a survivorship master plan that will include a history of the patient’s disease, including cancer staging and the treating physicians’ names, addresses and phone numbers; a summary of all treatments received; potential late effects that might be caused by the cancer treatments; a schedule of screening tests to monitor for disease recurrence; a list of lifestyle, behavioral and nutritional guidelines that may help prevent the cancer from returning; and referrals to specialists for those patients experiencing physical or emotional problems due to the treatments they received.

Most cancer care takes place in an outpatient setting, which hasn’t provided a comprehensive treatment summary to follow-up physicians. The survivorship care plan, however, will provide a treatment synopsis — similar to a hospital discharge summary but in this instance it will be given to patients as well as their physicians. This consultation will fill in a huge gap into which many survivors fall, Dr. Ganz notes.

“Survivors go back to their oncologists occasionally in the first years after treatment, but we need to be concerned about what happens to them five, 10, 15 and 20 years after treatment,” she says. “Right now, we’re not addressing that.”

In addition to the more than 2,000 newly diagnosed cancer patients seen by UCLA oncologists each year, the LAF grant supports a formal collaboration with Kaiser Permanente Southern California, HealthCare Partners Medical Group and Torrance Memorial Medical Center. This agreement will allow UCLA investigators to work with community partners to improve the quality of cancer-survivorship care within the greater Los Angeles region and will foster a wider range of survivorship studies in different types of healthcare systems with a richly diverse population of survivors.

“Solving the problem of how best to deliver coordinated and caring follow-up services within existing healthcare settings will not be simple,” Dr. Ganz says. “It will require teamwork among clinicians, researchers, healthcare executives, community leaders, survivors and others.”

Charlene Cottrell, clinical director of cancer programs at Torrance Memorial Medical Center, says that her hospital diagnoses and treats about 1,600 cancer patients a year. “In the past, we worked with our patients up and through treatment. Once they left, they were on their own,” Cottrell says. “Working with UCLA, we’ll be able to look at what more we can do for them.”

Likewise, George Gabison, director of the health-enhancement program for HealthCare Partners Medical Group, says participating in UCLA’s effort will help his medical organization improve the services they already offer.

In addition to working in the healthcare field, Gabison has a survivor’s perspective. He was diagnosed with bladder cancer in 1999 and felt he was excluded from the decision-making regarding his care. Without his background in healthcare, he says, he would have been completely lost.

“When my treatment ended, I had no summary of my care, and no one told me what to expect,” Gabison says. “Because of my background, I was able to take a proactive role.
But I suspect other patients have experienced what I experienced and need some help. This program will help patients feel more comfortable and become more involved in their treatment and follow-up care. That’s vital.”

Sheila McDaniel Henry, 41, of Playa del Rey, is a two-time cancer survivor, most recently beating breast cancer that may have resulted from treatment she received as a 17-year-old for sarcoma. Like Zebrack, she faced fertility issues; doctors told her that her chances of becoming pregnant were less than 1 percent. She suffered from fatigue and “chemo brain,” a disorder that at times muddled her thinking. She also suffered from bone pain. And like other survivors, she continues to worry about her long-term health.

“If I’m sick or fatigued or something doesn’t seem right, I’m very quick to jump to the conclusion that something serious is wrong,” says Henry, who raises money for research through her position with the Jonsson Cancer Center Foundation, a career path she chose because of her battles with cancer. “I know the cancer might come back, that’s always a possibility.”

Happily, Henry often is too busy these days to worry. Her “miracle baby,” Charlie, was born in 2004, and she is occupied with being a wife and mother. She, too, plans to be a part of the new survivorship center at UCLA.

“Survivors are out there,” she says, “and we’re living our lives.”

Zebrack is also enjoying a new life post-cancer. He now is married and the father of an adopted daughter, Sierra, 4. “The whole second half of my life will be radically different than the first half,” says Zebrack. “Cancer is life-changing, and this center, with its research-based approach, will change the way doctors deal with cancer survivors.”

Miranda also looks forward to representing the new generation of survivors. She entered Santa Monica College in the fall, where she is studying fashion design.

“I feel really proud to have gone through what I went through. I learned a lot from my cancer experience,” Miranda says. “I learned that I’m strong enough to overcome a challenge, and I hope that my experience and participation in the center will help the cancer patients who come after me. You can beat this disease and have a good life afterwards.”

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To watch videotaped conversations with some of the survivors and doctors interviewed for this article, visit http://streaming.uclalhealth.org/lifeaftercancer.