

Surviving and Thriving After Cancer Treatment



Specialized centers dedicated to the long-term health and well-being of cancer survivors are joining forces with the Lance Armstrong Foundation to set standards of excellence in survivorship care.

BY MIA JAMES

When cyclist Lance Armstrong claimed his seventh Tour de France victory in 2005, his record-setting win was made even more momentous by the fact that, less than 10 years earlier, the athlete had been diagnosed with testicular cancer, which had spread to his brain and lungs. What's perhaps most significant about Armstrong's story among cancer patients, survivors and their families, and healthcare providers is that the cycling champion is a survivor—one whose triumphant comeback from cancer underscores the fact that millions of Americans are surviving cancer diagnoses and living rich and active lives.

With survivorship, however, come new challenges. Bodies are permanently altered by the disease and its treatment, and survivors face the introduction into their lives of new social, financial, educational, and employment issues even as they leave treatment behind. Fortunately, the unique needs of the estimated 10 million cancer survivors in the United States are being addressed in winning form by the Lance Armstrong Foundation (LAF) LIVESTRONG® Survivorship Center of Excellence Network and the qualified survivorship programs that have earned LAF grants. Two such programs—Seattle’s Fred Hutchinson Cancer Research Center Survivorship Program and the Evanston Northwestern Healthcare (ENH) Living in the Future (LIFE) program in Illinois—are bringing cancer survivors continued care that addresses their long-term health and well-being. These particular programs also highlight the way that the LAF is serving cancer survivors at both comprehensive cancer centers and at the community level: as a comprehensive center, the Hutchinson program is a member of the LIVESTRONG Survivorship Center of Excellence Network, while LIFE is a recipient of an LAF community grant.

Survivors have been increasingly voicing their desire for the care that centers like these provide, and a 2006 report from the Institute of Medicine (IOM) illuminated the special concerns of this population. The IOM report called attention to the often-unmet needs of cancer survivors and outlined key elements of an effective survivorship plan. The IOM guidelines



DEBRA FRIEDMAN, MD

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proposed that each patient should have a detailed record of care received and disease characteristics along with a written follow-up plan. The plan should address recommended screening for new cancers and recurrences; possible long-term effects of treatment; effects on relationships, sexuality, and work; and the potential for insurance, employment, and financial consequences. Also included would be recommendations for potentially preventive lifestyle and nutritional choices and referrals to follow-up healthcare providers prepared to meet the unique needs of a cancer survivor. A comprehensive survivorship plan, according to the IOM, would also include information about and access to valuable resources.

The IOM guidelines clearly reflect the ongoing needs of survivors. So too does the mission of the LIVESTRONG Survivorship Center of Excellence Network, which—according to the foundation’s Web site (www.laf.org)—strives to utilize “the expertise, experience, creativity, and productivity of leading centers in an effort to significantly accelerate progress in the field of cancer survivorship.” Having earned a Centers of Excellence grant and a community grant, respectively, both the Hutchinson Center survivorship program and ENH’s LIFE program have been recognized by survivorship experts for their commitment to long-term care of cancer survivors. With their respective grants, the two centers serve as examples of effective



survivorship programs at both a major cancer center (Hutchinson Center) and in the community setting (LIFE).

Fred Hutchinson Cancer Research Center Survivorship Program

At the Fred Hutchinson Cancer Research Center Survivorship Program, director Debra Friedman, MD, is leading the institution's commitment to long-term, post-treatment care of cancer survivors. "As a cancer center," says Dr. Friedman, "we have recognized our responsibility to help patients take care of themselves for life."

With a goal of extending the same quality of care to cancer survivors as they received when they were newly diagnosed, the Hutchinson Center survivorship initiatives include long-term follow-up care for marrow and stem transplant recipients and programs for survivors of childhood cancer as well as prostate, breast, and ovarian cancers. Dr. Friedman also oversees the development of a program for general medical oncology survivors who have been treated with conventional therapy. All programs are based at the Seattle Cancer Care Alliance outpatient clinic. As a collaboration between three preeminent institutions (the Hutchinson Center, the University of Washington, and Children's Hospital and Regional Medical Center), the Seattle Cancer Care Alliance is poised to make significant strides in survivorship care.

The LAF grant strengthens the key initiatives of the Hutchinson Center Survivorship Program, including improved outreach to underserved communities. To this end three Hutchinson Center affiliates are being established outside of Seattle to provide high-quality care to inner-city, non-English-speaking Alaska Native and American Indian populations. These locations have been selected, Dr. Friedman explains, to reach diverse groups as well as those—as in the case of those served by the Alaska affiliate—who live far from a major medical center.

In addition to the program's reach and demographic diversity, Dr. Friedman is excited about what she calls a "cross fertilization" of



MARY TIETJEN

new research initiatives that will benefit the program. "As part of the LAF network of centers, we're able to collaborate with other centers to improve the lives of survivors."

For participants in the Hutchinson Center Survivorship Program, the number one advantage, according to 25-year-old Hodgkin's lymphoma survivor Melissa Vanloo, is peace of mind. As a busy mother of two young children, the Lynden, Washington, resident is grateful that her survivorship plan allows her to put much

of her worry aside so that she can focus on her family. "It's nice to know they're there and have so many valuable resources," says Melissa. She goes on to explain that the survivor healthcare providers at the Hutchinson Center "know the drugs well and know what to look for as far as side effects and recurrences." She's confident that her annual follow-up is conducted with a keen, expert eye.

Melissa is also aware that, due to her history of Hodgkin's disease and its treatment, her body is quite different from that of a 25-year-old who hasn't experienced cancer. Nutritional advice has thus been particularly valuable: "With nutritional guidelines that address exactly how my body has changed, I learn about certain nutrients that can help build back what cancer drugs have depleted."

Mary Tietjen of Port Townsend, Washington, is another participant in the Hutchinson Center program. Having faced a diagnosis of Stage IIA breast cancer in 1998 and treatment that included a mastectomy, chemotherapy, radiation, and tamoxifen (Nolvadex®), the 59-year-old retired marketing executive says, "What this program has done the most for me is keep my attitude positive." Her survivorship plan, Mary explains, focuses on "making sure I'm going to be healthy 10 years from now—body and soul," and offers both medical support and nutritional guidance that keeps her informed about the latest advances and research in survivorship care. A focus on clinical trials for survivors, for example, has led to Mary's participation in a study for the early detection of ovarian cancer and, currently, to a trial researching the use of Aromasin® (exemestane) following tamoxifen.

For survivors like Melissa and Mary, the Hutchinson Center Survivorship Program supports their journey from active cancer care back to the primary and family care setting, a process that, when unaided, can leave survivors “caught in transition,” says Dr. Friedman. Thorough screenings and health evaluations and a personalized survivorship plan (copies of which are provided to their medical oncologists and primary care physicians) are aimed to bridge the gap between oncologists and primary care providers by allowing for a comprehensive sharing of information across both healthcare sectors.

Although medical oncologists possess expertise in cancer and the long-term effects of its treatment, the demands of caring for acute patients leave little opportunity to care for survivors. Primary care physicians, on the other hand, will best serve their patients when they have greater understanding of the impact of cancer on basic health. To maintain this connection between phases of care, medical records are carefully reviewed, a comprehensive physical exam is conducted each year, and referrals are made to specialists or for testing when appropriate. Furthermore, says Dr. Friedman, a survivorship plan ensures that survivors never feel alone once active cancer treatment is completed; survivorship care offers participants “someone who is always listening and who will let them tell their story.”

To learn more about the Hutchinson Survivorship Program, please visit www.fhcrc.org/patient/support/survivorship.

Living in the Future at Evanston Northwestern Healthcare

Although the Hutchinson program and its community-based affiliates demonstrate that major cancer centers can successfully reach individual communities, many community centers themselves are establishing survivorship programs. As



NURSE CAROLE MARTZ WITH SURVIVOR HELEN HACKETT

Dr. Friedman said of the benefits of belonging to the LAF network of survivorship centers, the opportunity for major institutions and community centers to share information is central to advancing survivorship care.

For Carol Rosenberg, MD, FACP, founder and director of LIFE, the survivorship program at ENH in Illinois, this collaboration translates into a community service that is “grassroots with an evidence-based core.” In other words, LIFE is designed to meet the specific needs of the community it serves while its protocols stay in step with leading research. The result is progressive, individualized care that Dr. Rosenberg describes as “by the community, for the community.” LIFE joined LAF’s network of

survivorship centers in 2006 when it received one of 27 LAF community program grants offered that year.

The first survivorship program in the Chicago area, LIFE began with a focus on breast cancer when it opened its doors in 2006; it plans to serve survivors of all cancers during its second year of operation. LIFE adheres closely the IOM survivor care guidelines in its commitment to contribute to the development of survivorship care as a distinct phase in the cancer care continuum. Like the Hutchinson program, LIFE creates a bridge between initial treatment and post-treatment care. It connects survivors to primary care physicians and local support networks and resources as they leave intensive treatment and, as Dr. Rosenberg says, would otherwise move forward “without a healthcare escort.”

LIFE thus becomes the survivor’s guide, beginning with a personalized visit with Carole Martz, RN, MS, AOCN, whose area of expertise is cancer survivorship. Information from this personal visit is combined with research of relevant medical history to create a portable written record of the survivor’s diagnosis and treatment plan, guidelines for continued monitoring, preventive recommendations, and appropriate

resources (such as those relating to fertility and genetics)—a combination of information that Nurse Martz says leaves survivors “feeling empowered.” She also explains that the timing of this visit is crucial, allowing her to “take advantage of a teachable moment” when survivors may be anxious about their next healthcare steps and eager to be educated and proactive about ensuring their future health.

According to Dr. Rosenberg, the Evanston program has revolutionized survivorship care by putting this portable detail into electronic form to make sharing of information between survivors and their healthcare providers more efficient. Nurse Martz also explains that ENH’s electronic system expedites survivor care planning from the beginning by giving her access to a patient’s treatment and healthcare information before their first meeting. This is an area of development where LIFE has actually surpassed the progress of larger centers, which have used LIFE’s template to create their own electronic records.

LIFE also reaches out to serve the larger community with regular seminars addressing common concerns of cancer survivors. Titled the “Survivorship 101 Seminar,” the series begins with “Thrivership: Navigating Survivorship—A Roadmap for LIFE.” This initial discussion covers major aspects of survivorship as well as an introduction to navigating community-based survivor resources. Additional seminars, which will focus on distinct survivor concerns, include “Eat to Beat Malignancy and Walk Away from Cancer” and “Self-esteem and Sexual Intimacy After Cancer.” More survivorship information can be found at www.enh.org/life, where visitors can also view the latest survivor news and find online resources.



HELEN HACKETT TEACHING A SPINNING CLASS

In addition to seminars and standard programs, LIFE maintains awareness that each survivor’s challenges will be determined by his or her age at diagnosis, type and severity of cancer and treatment, financial situation, access to follow-up care, and employment and educational concerns. Each of these issues factors strongly as the LIFE team builds individual plans that support each survivor’s successful transition from cancer treatment to “living in the future.” The personal quality of LIFE, Dr. Rosenberg explains, can be credited to the fact that each member of the faculty and staff is linked to cancer survivorship, either personally or through a family experience. Dr. Rosenberg herself is the parent of a young adult cancer survivor, which deepens her personal commitment to the program and the pride she takes in its progress.

Survivor Helen Hackett, 49, is enjoying the support and the educational offerings of the LIFE program so much that she can’t imagine negotiating her post-treatment healthcare without it. “I wonder what the heck survivors did before this program!” the fitness instructor interjects as she explains how she utilizes LIFE and what she’s learning from it. Following her breast cancer diagnosis through a mammogram and her treatment that included lumpectomy, chemotherapy, and radiation, Helen has met with Nurse Martz to review her medical history and discuss nutrition and exercise. She has attended seminars, and she consults with Dr. Rosenberg and Nurse Martz about such topics as the latest cancer news and finding a primary care provider who is qualified to attend to her needs as a cancer survivor.

As a fitness instructor, Helen appreciates LIFE’s nutrition, lifestyle, and exercise data in particular. Knowing that positive

More Good News for Survivors



The Lance Armstrong Foundation (LAF) announced this April that it had recently awarded more than \$4.1 million in grants to support cancer survivorship research projects, the basic and clinical research of testicular cancer, and community-centered cancer survivorship initiatives across the country.

The LAF's latest grant funding includes an additional \$244,400 in grants to five community-based, nonprofit organizations for cancer survivorship programs, which will complement the nearly \$1 million in community program grants awarded last fall. Included in the community grant are programs that address common women's concerns, such as an intervention project to reduce fatigue, weight gain, and cancer recurrence rates (Mercy Medical Center in Cedar Rapids, Iowa) and a project to provide breast cancer survivors with care packages that address their specific needs and ongoing health concerns (Pennsylvania Breast Cancer Coalition).

"Through our grant program, the LAF focuses on improving quality of life for people affected by cancer," said Suzanne Kho, director of grants for the LAF. "We are delighted to support community organizations and researchers at institutions across the country in their efforts to help cancer survivors face the challenges and changes that come with cancer."

Other LAF-funded cancer survivorship research studies will explore quality of life among African-American head and neck cancer survivors, chronic pain in cancer survivors, the prevention of diabetes in prostate cancer survivors, and cancer survivors' intentions to work following diagnosis and treatment.

Since its inception the LAF has invested more than \$18.7 million in research grants and more than \$4.8 million in grants to community-based, nonprofit organizations.

For more information about the LAF's grant funding, visit www.livestrong.org.

changes may decrease her risk of recurrence, she says, "gives me a sense of security," explaining that "if we can't control whether cancer will recur, we can take comfort that we can make choices that may reduce our risk." Examples of these choices that Helen says have been covered in LIFE seminars include limiting red meat and alcohol intake, exercising, and maintaining a healthy body weight.

In these recommendations and so much of LIFE's curriculum, Helen says the message is empowering, which aligns with the theme of "knowledge is power" that Dr. Rosenberg says drives their educational goals. It is with this proactive approach to survivorship that LIFE aims to lead the way to long, healthy lives after cancer because, asserts LIFE's founder and director, "It isn't over when it's over." And with those words, she confirms that the ever-growing population of survivors has the potential for long, rich, and healthy lives beyond a cancer diagnosis. ✿

To learn more about Living in the Future at Evanston Northwestern Healthcare, please visit www.enh.org/life.