



NAVIGATING THE CANCER EXPERIENCE WITH THE HELP OF THE LANCE ARMSTRONG FOUNDATION

JULY 2012

“LIVESTRONG guided me through a very complex system. The navigators are the cream of the crop, helping you through the process.”
Heather, 36, Desmoid Sarcoma Survivor

Across the globe, 28 million people are affected by cancer. Each of these individuals has a personal experience with the disease. The Lance Armstrong Foundation (Foundation) can help those diagnosed, their loved ones, and their caregivers and health care providers navigate the cancer experience by helping to address questions about treatment, clinical trials, insurance, emotional concerns, financial concerns, and other issues that arise.

The Foundation’s cancer navigation services provides comprehensive one-on-one services nationally, free of charge, in English and Spanish. Cancer care is fragmented in the United States, and the Foundation aims to facilitate comprehensive connections for those affected by cancer so they can focus on their fight. Navigation services are customized to the individual and provided by professionals.

The Foundation believes in collaborating with experts in the field, rather than duplicating services. Since launching its navigation services in 2004, the Foundation has partnered with organizations that provide specialized services to address

the needs identified by constituents. Included in the original partnership are:

- Patient Advocate Foundation, a national nonprofit that provides assistance for the uninsured and underinsured, access to medical treatments, assistance handling debt and financial management issues, and assistance handling employment discrimination/retention issues; and
- EmergingMed, an organization that provides information about treatment and clinical trial options and matches people with clinical trials.

Addressing Service Gaps

The NavigateCancer Foundation joined the partnership in 2011 to address the high volume of client requests for assistance understanding their diagnosis and making decisions about medical care. Oncology nurse navigators are now available to help those affected by cancer understand their medical documents and make decisions about their next steps in care.

Additionally, Imerman Angels joined the partnership in 2011 in response to clients expressing to navigators their

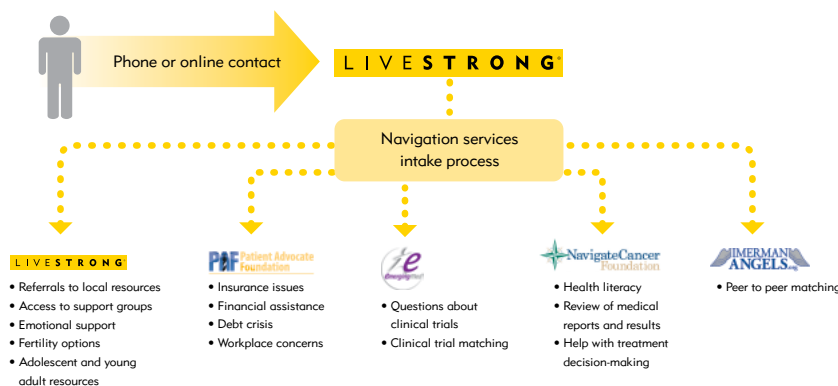
interest in talking with others who shared similar experiences, not just in terms of diagnosis and treatment but of life circumstances such as family structure or geography. To help meet this need, we partnered with Imerman Angels, a nonprofit that pairs cancer fighters, survivors, and caregivers with mentor angels.

The Foundation contributes to this partnership model by providing supportive educational materials, information on cancer’s impact on fertility, emotional support provided by licensed social workers, and overall care coordination among partnering organizations (see Figure 1).

Impact in Numbers

Each year the Foundation’s cancer navigation services helps increasing numbers of people comprehensively address the myriad concerns that a cancer diagnosis brings. In 2011, 13,706 people affected by cancer were served (see Figures 2, 3). This is 22 percent more than the number of people served in 2010 (see Figure 4). On average, individuals received at least three cancer navigation services. These services addressed client-identified top concerns, such as financial assistance, diagnosis and treatment information, and emotional support.

FIGURE 1: NAVIGATION PROCESS



Age	% of Austin Respondents	% of National Respondents
0-14	0%	0%
15-17	0%	1%
18-25	6%	11%
26-39	27%	36%
40-50	29%	26%
51-64	29%	21%
65+	9%	5%

FIGURE 2: AGE OF CLIENTS

Ethnicity	% of Austin Respondents	% of National Respondents
African American/ Black	3%	5%
American Indian/ Alaska Native	0%	1%
Asian	1%	3%
Caucasian/ White	38%	65%
Hispanic/ Latino	56%	23%
Native Hawaiian/ Other Pacific Islander	0%	0%
Mixed Race	1%	2%
Other	0%	1%

FIGURE 3: ETHNICITY OF CLIENTS

Indeed, cancer’s financial impact on a person can be significant; many survivors struggle to stay on top of their finances during and after treatment, as evidenced by navigation clients identifying financial assistance as the top need. In response, the Foundation’s cancer navigation services connected clients to monetary awards and helped them save money by negotiating discounts, maximizing medication programs, and overturning insurance denials. Specifically, cancer navigation services facilitated fertility preservation assistance (such as egg/ embryo freezing, sperm banking, and long-term storage) for clients by negotiating discounted rates with fertility centers and sperm banks and providing donated medications for women. The impact of these financial services totaled more than \$3 million in savings.

LIVESTRONG Cancer Navigation Center

In 2011, the Foundation opened the LIVESTRONG Cancer Navigation Center expanding service modalities from online

FIGURE 4: PEOPLE SERVED NATIONALLY

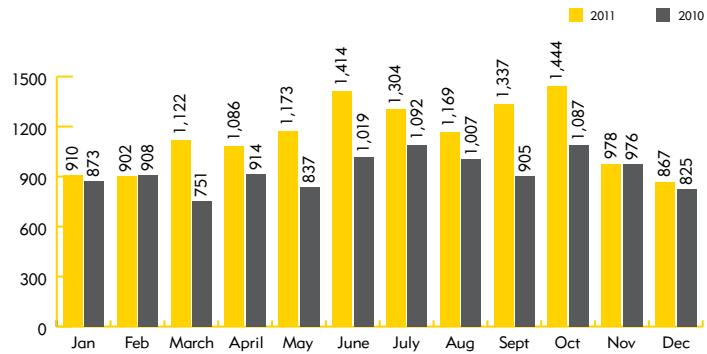
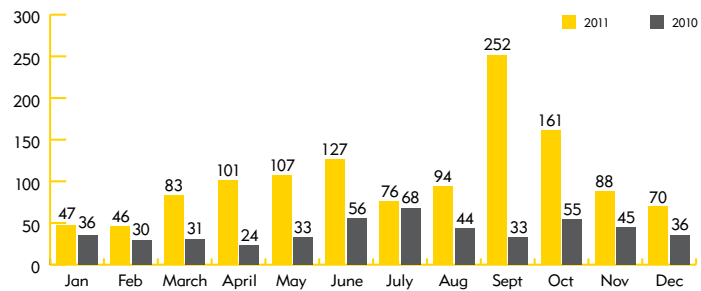


FIGURE 5: PEOPLE SERVED LOCALLY



and phone to include in-person visits. The Center is located next door to the Foundation headquarters in Austin, Texas. The introduction of this service modality helped the organization serve 155 percent more Austin-area residents than were served in 2010 (see Figure 5). Of the 1,252 Austin-area residents served, nearly 25 percent utilized cancer navigation services by visiting the Center.

Like the clients the Foundation serves nationally, those affected by cancer in the Austin area have a high need for financial and insurance assistance. In response, the Center was able to connect clients to more than \$84,000 in savings.

While the needs of Austin clients were consistent with those of the Foundation’s national clients, Austin clients were more likely to be age 40 or older (67 percent) and identify as Hispanic/Latino (56 percent). Only 23 percent of national clients identified as Hispanic/Latino,

demonstrating the effectiveness of our targeted outreach to the Austin community. Learn more about this in the LIVESTRONG Hispanic/Latino Case Study at LIVESTRONG.org.

Raising Awareness

The Foundation will continue to listen and respond to the needs identified by clients to ensure that it continues to create strategic partnerships and resources that will help meet those needs. In addition, we feel it is important to be a voice in the community for better care coordination for those affected by cancer, particularly in communities where comprehensive cancer centers are not available. Over the next year, the Foundation will develop plans for educational training modules to help other health care professionals and organizations have an active role bringing community navigation where needed.

ABOUT THE LANCE ARMSTRONG FOUNDATION

The Lance Armstrong Foundation serves people affected by cancer and empowers them to take action against the world’s leading cause of death. With its iconic yellow LIVESTRONG wristband, the Foundation became a symbol of hope and inspiration to people affected by cancer throughout the world. Created in 1997 by cancer survivor and champion cyclist Lance Armstrong, the Foundation provides free patient navigation services to survivors with financial, emotional and practical challenges that accompany the disease. Known for its powerful brand – LIVESTRONG – the Foundation is also a leader in the global movement on behalf of 28 million people living with cancer today. Since its inception in 1997, the Foundation has raised close to \$500 million for the fight against cancer. TO LEARN MORE VISIT LIVESTRONG.ORG.