



PATIENTS OF A DIFFERENT STRIPE

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When I was 26 years old, I began having excruciating pain in my left ankle that woke me up, night after night, for eight months. Four doctors, one physical therapist, hundreds of anti-inflammatories, numerous x-rays, whirlpool treatments and ultrasound treatments later, I was diagnosed with Ewing's sarcoma, a rare type of bone cancer that typically occurs in children.

I was treated on a pediatric treatment protocol in an adult hospital, surrounded by patients my grandparents' age for the entire 18-odd months of chemotherapy, radiation and recovery. I was lonely, scared, and facing the fight of my life in a place that didn't seem to expect me and didn't accommodate my needs in any way.

There was no way to find people who were in the same boat: people who understood what it was like to move back home with my parents after gallivanting around the world for three years. People who didn't know whether they would ever be able to have a family after this—or if anyone would want to have a family with them. People who, like me, were learning to question doctors, deal with billing departments, and face their own mortality for the first time, while our friends were deciding which happy hour to hit.

Although I like to think that I am unique and special, in many ways my story is a tired repetition of the typical young person with cancer's story: low clinical suspicion, delayed diagnosis, no peer support, no age-appropriate support services or resources, no fertility information, no clinical trial options, and no clues given as to how this experience could or would impact the rest of my life.

To put it simply, young adults like me with cancer have fallen through the cracks on every front: scientific, emotional, clinical and financial.

In Dr. Jerome Groopman's new book, *How Doctors Think*, he discusses the following mantra, frequently relayed in medical school: "When you hear hoofbeats, look for horses, not zebras." Well, that's fine. Unless you're the zebra.

For starters, to identify the zebra you have to acknowledge that it is, in fact, different from a horse. And in many ways the unique aspects of young adulthood are as obvious as those black-and-white stripes: from emotional needs, developmental stages and

biologic differences, to age-specific issues related to access and delivery of care.

Even so, until quite recently, young adults were not identified as a distinct demographic group, but were lumped in with their younger and older counterparts. However, when you break them out, young adults are quite the sizeable herd: in fact, there are more than half a million cancer survivors in this age group. Nearly 70,000 patients are diagnosed annually in the U.S. between the ages of 15 and 39, and cancer is our number-one natural cause of death.

Even more startling is the fact that, despite impressive improvements in survival rates for older and younger patients, young adults have not kept pace. In fact, survival rates for 25-35 year olds have remained absolutely flat for the last three decades.

Unfortunately, even faced with these distressing statistics, the medical community as a whole has not yet rallied on our behalf. One of the most gaping omissions is evident in the lack of young adult inclusion in clinical research, where we are the least-represented demographic group.

This is a critical omission when you consider that identifying the biologic differences in young adult cancer can significantly impact treatment strategies and outcomes. And although these unique biologic characteristics are starting to be addressed in some cancers, such as acute lymphoblastic leukemia (ALL) and breast cancer, in too many other cancers it is not known why young adults do not respond to treatment in a similar fashion as our older and/or younger counterparts with the “same” disease.

Of course, effective treatments are only as good as the access and care delivery system that gets them to the patient. And—once again, the refrain—young adults are different. Our medical care can be complicated by the fact that we are the most likely patients to be under- or uninsured, too old for our parents’ or government insurance, yet maybe not in an established career with benefits. We must balance treatment schedules with school or work (in many cases necessary to hang onto insurance), dating, young families and aging parents.

And when you look down the road of a lifetime at what these half a million young survivors will face for the next 50 years? Fertility challenges, fear of recurrence, disclosure issues, altered life goals and priorities, the challenge of insurance hassles and employment issues, and the never-ending need for diligent medical attention and follow-up—all things that set the young adult cancer survivor apart from his or her peers.

But things are looking up in the young adult cancer world, where there is a growing movement to acknowledge the zebras that have been camouflaged for too long. Like me, many young adults have formed organizations to address specific issues of the young adult cancer patient. There has been much progress in recent years as we have, finally, discovered each other and banded together-- many under the umbrella of the [LIVESTRONG Young Adult Alliance](#) a coalition whose mission is to improve survival rates

and quality of life for young adults with cancer between the ages of 15 and 39.

Initiatives such as SU2C bring hope by breaking out of the traditional research mold, which has, to put it bluntly, failed most young adult cancer patients. “Dream teams” for research could provide and even provoke tremendous opportunity for us at a time when young adults are knocking on the door, demanding our rightful place at the table. As a group, we are standing up to say: *Young adults DO get cancer. We DO have unique needs and issues. DO NOT let us fall through the cracks for ONE MORE MINUTE.*

Here comes the stampede. Watch out.

Heidi Schultz Adams is a 13-year survivor of Ewing’s sarcoma. She is the founder and executive director of [Planet Cancer](#), a non-profit organization dedicated to creating a community of young adults with cancer in their 20s and 30s, and to raising awareness about their unique medical and psychosocial needs. She is a founding member and the advocacy co-chair of the [LIVESTRONG Young Adult Alliance](#) a national coalition of organizations working together to improve survival rates and quality of life for young adults with cancer. Heidi served on the planning committee of the 2006 Adolescent/Young Adult Oncology Progress Review Group, a joint initiative of the Lance Armstrong Foundation and the [National Cancer Institute](#) In 2005, she received the prestigious LIVESTRONG Award from the Lance Armstrong Foundation for her work on behalf of young adults, and in 2006, she was named a Swiffer Amazing Woman of the Year. In 2007, she was recognized as one of four national Health Heroes by [WebMD magazine](#) A writer by profession, Heidi is also a contributor to [CURE magazine](#) and is the co-author of [Here and Now: Inspiring Stories of Cancer Survivors](#) published in 2001 by Avalon.