

# THE WALL STREET JOURNAL.

WSJ.com

NOVEMBER 9, 2010

## 'Too Young for Cancer' and Demanding Action



Jesse Horton

Neil Taylor, who was left blind after brain-tumor surgery, navigates the Colorado River on a trip with First Descents, which takes cancer patients on adventure outings.

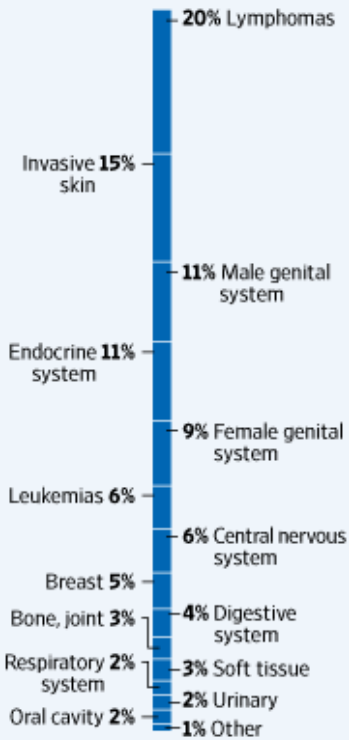
The grim statistics have become a rallying point for activist groups: Some 72,000 Americans aged 15 to 39 are diagnosed with cancer every year, and more than 10,000 die. They make up less than 10% of all cancer patients, but survival rates for teens and young adults have barely budged since 1975, while those for children and older people have made dramatic gains.

Now progress is slowly being made toward understanding that age gap and creating a niche for young adults in a system that has been starkly

divided between pediatrics and adult care, where the average cancer patient is 67 years old.

### When Cancer Strikes

A breakdown of the types of cancer that affect people aged 15 to 29 in the United States:



Source: National Cancer Institute (data 1975-2000)

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Judging from recent death statistics, "there's a hint that survival rates are beginning to improve in this adolescent and young-adult group," says Archie Bleyer, a pediatric oncologist at St. Charles Medical Center in Bend, Ore., who first noticed the survival disparity in 1996.

Dr. Bleyer was one of more than 100 medical experts and activists at a meeting in Austin, Texas, last week of the Lance Armstrong Foundation's Young Adult Alliance, an umbrella organization of groups devoted to adolescent and young-adult cancer.

Among other signs of progress: In March, a new medical journal, *Adolescent and Young Adult Oncology*, launched. And two articles in the *Journal of Clinical Oncology* this week call for creating a new medical discipline addressing adolescent and young-adult cancers and setting quality of care standards.

Many of the 66 National Cancer Institute-designated cancer centers are each appointing a physician from pediatrics and from adult care to help coordinate care for patients 15 to 39. "A lot of it is just about communication—making sure that if a patient in this age range, you know who to go to get the best care," says Nita Seibel, a pediatric oncologist at NCI focusing on adolescent and young adult cancers.

Cancer is especially lethal in young adults for many reasons. One is delays in diagnosis. While older patients have benefited from early diagnoses, doctors seldom suspect cancer when young adults have symptoms like headaches, fatigue or bone pain. Young people themselves often ignore symptoms, so their cancers tend to be far advanced when they finally are detected.

What's more, young adults are the least likely to have health insurance, limiting the care they receive. And few participate in clinical trials, so there's little data on the best treatments for them. "Almost everything we've learned about treating cancer came from clinical trials," says Dr. Bleyer, who notes that there are more trials for infants with cancer than 20- to 25-year-olds.

Because of the lack of data, young adults are

typically treated with the same cancer regimens developed for much older patients. But there's growing speculation that they can tolerate more intensive therapies that could give them a better chance for survival.

One early hint came from studies overseas showing that when young adults with acute lymphoblastic leukemia (ALL) were treated with the intense drug therapy developed for children, their survival rate was 80%—nearly double the rate for those on the adult regimen. Now a major trial is under way at about 1,000 U.S. cancer centers to test the pediatric regimen in ALL patients aged 15 to 39.

"In general, the older the patient, the greater the need to be gentle and maintain quality of life during the treatment," says Dr. Bleyer. But up to age 40 or 50, most patients are more like adolescents than older people, he notes. "By applying the same philosophy that we apply to older people, we are under-treating young adults, who could tolerate more."

Scientists are also probing whether the cancers that occur in adolescents and young adults are biologically different from those in younger or older patients. To date, there have been very few samples to study. The Lance Armstrong Foundation is funding an effort to gather existing samples, and the National Cancer Institute is starting a repository to collect more.

Besides biological differences, there's a growing recognition that young adults with cancer face unique psychological and social issues that aren't being met in traditional cancer settings.

Should you continue your pricey education? Move back in with your parents? Should you throw marriage and childbearing into fast-forward, or put it on hold? When, and what, do you tell a prospective employer—or a date?

"Some young people I interview say [their diagnosis] is the first thing out of my mouth—and if the other person can't handle it, then adios," says Brad Zebrack, an associate professor of social work at the University of Michigan who works with young cancer patients.

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One major issue is fertility. Some cancer treatments end or compromise patients' future fertility, but many young adults aren't forewarned and given the option of freezing their sperm or eggs.

Some centers have started to designate specific teams of physicians, nurses and social workers to work with young adult patients—and in some cases, whole departments devoted to them. "We have totally changed our approach," says Brandon Hayes-Lattin, medical director of the Knight Cancer Institute Adolescent and Young Adult Oncology Program at Oregon Health and Science University. One physician there is pursuing a combined fellowship in pediatric and adult oncology. The center also has a clubhouse for young adults, with treadmills, a Wii and a big-screen TV.



Irreverent merchandise like this T-shirt is available through the I'm Too Young for This website.

Experts concede that such programs are still the exception. "We have made great strides," says Leonard Sender, medical director of the Children's Hospital in Orange County, Calif., who helped draft a "bill of rights" for young-adult cancer patients, including the right to be taken seriously, the right to fertility information and the right to financial and practical support. "Still, way too many patients do not get access to care at a place

that understands the difference."

Much of the momentum for the change has come from a burgeoning movement of young cancer patients themselves, speaking out—often irreverently and impatiently—about their frustrations with the current system. Dozens of support groups, websites, chat rooms and blogs—some with names like "Tumors Suck!"—showing young cancer patients they are far from alone.

"It's the language that young people can relate to," says Dr. Zebrack. "They're scared and they've gone through months and months of doctors telling them, 'Don't worry.' "

One pioneer was Heidi Schultz Adams, who was diagnosed in 1993 with Ewing's sarcoma, a cancer that often occurs in the bones or soft tissue, at age 26. In 14 months of treatment at a Dallas hospital, "I only met four people my own age, and three of them died," she says. "One day I heard someone playing U2's 'Joshua Tree' and I went up and down the hall in the hospital thinking, 'At last—someone like me!'"

In 2000, Ms. Adams founded Planet Cancer, one of the first outreach groups for young adults, providing message boards and a forum for discussions on such issues as, is it OK to be buried in jeans? Planet Cancer set an irreverent tone for the movement early on with cancer-related Top 10 Lists (Worst Ways for an Oncologist to Break the News: 4. "You have cancer. The nurse will fill you in.")

"The Internet was just starting, and it allowed us to find each other," says Ms. Adams, now 43 and the mother of 6-year-old twins.

Matthew Zachary's group, the "I'm Too Young For This" cancer foundation, also known as I[2]Y, is more strident. "We give angry young adult survivors a home," he says. A rare pediatric brain cancer shattered his budding career as a concert pianist at age 21. When he heard about the grim survival statistics in 2005, he turned to activism instead. "I wanted to help the next me," he says.

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Associated Press

A charity walk featuring former Philadelphia Phillies pitcher Mitch Williams in August was a fund-raiser for the Lance Armstrong Foundation, which finances research efforts to help young adults with cancer.

Links on I[2]Y's website include "I'm all alone," "I need money," "I can't work" and "I need a break." Its many activities range from selling T-shirts with slogans like "eyebrows are for losers," and to sponsoring an annual oncology conference—called the OMG! Cancer Summit—for young adults. Mr. Zachary is also co-host of radio's "The Stupid Cancer Show," whose audience has ballooned from 300 in 2009 to nearly 400,000 this year.

Other groups have sprung up to address specific needs of the young-adult population. Fertile Hope provides assistance—including an online risk calculator—to cancer patients whose fertility might be compromised by their treatment. Cancer and Careers offers tips about dealing with clients and coworkers, as well as legal and financial advice. Imerman Angels pairs cancer patients, and caregivers, with others who have had similar experiences.

First Descents of Vail, Colo., takes cancer patients age 18 to 40 on week-long rock climbing or kayaking trips, free, no matter how sick or disabled they may be. "The idea is, if you can manage whitewater rapids, you can manage anything," says professional kayaker Brad Ludden, who founded the group in 2001 when he was 18.

"It was such a rush," says Neil Taylor. Brain-

tumor surgery left him blind at age 28, but the former college lacrosse player jumped at the chance to kayak, solo, down the Colorado River with a First Descents trip in August. "Kayaking is a sport blind people can do. You can feel the flow of the water, and the way the rapids are taking you. I am totally going next year."

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