

Patients, families turn pain into efforts to fund research

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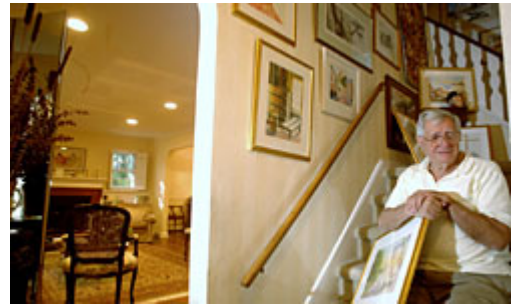
Before she died of pancreatic cancer last spring, Yvette Strauss asked her daughter to sell cards made from her paintings to support research for a cure.

The family of the late Ron Weber has organized a walk in Paramus on Sunday with the same heartfelt goal.

And Lauren Lee, a rare 14-year survivor of inoperable pancreatic cancer, brings a special mission to the cause: showing why patients should never give up. "I am very happy," she says. "I enjoy every day and live it like it's my last."

All these people are determined to raise money to beat one of the most lethal kinds of cancer. They want something positive to come from their pain. That's why I'm writing about life with my husband's pancreatic cancer, too. I share their sense of powerlessness in the face of a nearly invisible enemy, one we have no routine tools to detect early and few effective ways to fight.

What makes all this even more aggravating is the relative dearth of money to investigate a cancer that kills 95 percent of its patients within five years.



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Ira Strauss holding a watercolor painted by his wife, Yvette. The family sells cards made from her paintings to raise funds for pancreatic cancer research.

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Pancreatic cancer is the fourth leading cause of cancer death in the United States, after lung, breast and colon cancer, but it gets only a sliver of cancer research money, and much less than the other major killers. The largest source of federal funds for cancer research, the National Cancer Institute, allotted \$74 million last year to projects directly related to pancreatic cancer. That's about 1.5 percent of its budget.

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We are very lucky that my husband, Elliot, is here today, 14 months after diagnosis. Only 25 percent of pancreatic cancer patients survive a year. I can write this story now because his devoted, terrified mother, who waits by her phone for reassurance after every one of his biweekly doctor visits, has wisely chosen not to read this series. Seeing these statistics certainly wouldn't help her. Wrestling with them myself makes me furious, defiant or depressed, depending on the day.

Lauren Lee, of Upper Saddle River, warns me away from the ugly numbers. She makes a point of telling her story on cancer Web sites to encourage anyone in despair. She had a 3-year-old daughter when she was diagnosed at age 40, and was determined to see her little girl turn sweet 16. After three arduous years of aggressive chemo and radiation, Lee heard a glorious verdict: "No Evidence of Disease."

"Everyone is different," Lee insists. "Don't listen to statistics."

Good advice; not easy to follow. It's hard to square the fun days, when Elliot laughs with me over our earnest but sloppy tennis games, with the draining ones after chemo, when he drenches his pillow with sweat.

"Hope for the best, but be prepared," my doctor told me at a checkup. At least Elliot has a lot going for him: He's young for this ordeal -- 56 -- and strong and resolute.

No clear predictions

Doctors can forecast the outcome for a group of people with pancreatic cancer, but they can't make clear predictions about any one patient. The bleak odds overall, however, have spurred desperate families to push for more resources to decipher this baffling disease.

Yvette Strauss wanted her artwork to help. She left behind dozens of pastel watercolors of flowers and seascapes which decorate the Tenafly home where she raised a family with her husband, Ira. Now the house is still and quiet. All you can hear is the loud, slow tick of an antique clock. Her paints still sit in a canvas bag on the floor. Profits from sales of cards made from her work (at yscards.com) will go to pancreatic cancer research.

"I hope it helps," Ira Strauss says simply, choking up. "Painting kept her busy, gave her something to look forward to. ... A lot of afternoons I'd just hold her so she could sleep."

Scientific understanding of pancreatic cancer lags way behind other major cancers, and advocates say the country needs to invest far more to improve diagnosis, treatment and prevention. An estimated 37,170 Americans will find out they have pancreatic cancer this year and 33,370 people will die from it. Only a fraction of cases -- some say 15 percent -- are caught early enough to be eligible for surgery, the best chance for a good outcome.

It's tough to muster support for the cause when many people barely know where the pancreas is (behind the stomach) or what it does (produces insulin and enzymes for digestion.) Moreover, there are few survivors to march on Washington. There are few celebrities who can make stirring speeches about how the illness affects them, the way actor Michael J. Fox advocates for Parkinson's disease. Mourning over the loss of opera star Luciano Pavarotti this month put the spotlight on pancreatic cancer for only a fleeting moment.

"Surely we can't have a funding system that relies on having celebrities," says Megan Gordon Don, director of government affairs at the Pancreatic Cancer Action Network, or PanCAN.org. "We've made tremendous progress in getting our message out there but we're really just beginning."

She underscores that her group does not want to drain resources from other diseases. Instead, advocates representing different cancers have bonded together in "One Voice Against Cancer" to lobby Congress and the White House for help. Now OVAC is calling urgently for a 6.7 percent boost for the National Cancer Institute budget, to get \$5.1 billion for the fiscal year that starts Oct. 1.

"We work very hard to make sure we don't get caught up in the 'disease wars,' " Don says.

Few eligible for study

Advocates say this is a crucial time to invest. "There are some really exciting things happening in the lab," says Elizabeth Thompson, director of research at PanCan. "Now we need money to take them to the bedside."

National Cancer Institute spokesman Michael Miller explains that pancreatic cancer research gets less money than other cancers partly because it's relatively uncommon, so there are fewer patients eligible for studies, and many don't live long enough to be observed long-term.

What's funded depends largely on what promising projects are proposed by scientists, he says. Some advocates see a chicken-and-egg dilemma, however, and counter that it's hard to draw scientists into this challenging specialty if sufficient resources aren't available.

Miller points out that NCI funding for pancreatic cancer research has more than doubled since 2002. Furthermore, discoveries made when investigating one kind of cancer are often illuminating for other kinds, so funds for pancreatic trials don't represent all the efforts that might prove relevant.

When Marc Lustgarten, a top Cablevision executive, got pancreatic cancer, he vowed to support more studies. He died in 1999, but the Lustgarten Foundation for Pancreatic Cancer Research has committed \$18 million so far.

Ron Weber's family took the same mission to heart. Weber, who was business administrator for Ridgefield Park schools and served on the Paramus school board, died of pancreatic cancer two years ago. He was 63.

His wife, Jeanne, was so moved by the uplifting atmosphere of a Lustgarten Foundation walk in New York last year that she decided to host one at home. Registration starts at 8:30 a.m. for the 10 a.m. walk Sunday in the Dunkerhook area of Saddle River County Park in Paramus.

One afternoon this week, her dining room table was piled with handmade signs. Family and friends have put up fliers. Local sponsors are donating coffee, juice and bagels. The phone keeps ringing. She believes her husband would be proud of this walk, and honored.

"I'm very excited about it, but every now and again I realize why I'm doing it," says Weber, wiping her eyes. "It becomes overwhelming."

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