

Son finds hope for dying father on Internet

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Anup Savla scoured the Internet for

something to save his father, who was dying in India from a devastating brain cancer. He ended up at a U.S. government Web site, where he learned about an experimental vaccine being tested at Stanford University.

A month later, his father flew in from Mumbai, India, and today Harakhchand Savla is part of a Stanford clinical trial researching a drug that might add years to his life.

"In a way, we got extremely lucky," said his son, who lives in San Mateo. "It's all about the online research."

The Internet is making connections possible that didn't happen before. Now Stanford is marketing its clinical trials directly with its own all-inclusive Web site, med.stanford.edu/clinicaltrials.

Researchers hope the Web site will help overcome one of their greatest challenges: finding volunteers such as Savla to take part in research for cures and new medicines.

"The primary reason trials fail? Not enough subjects," said Steven Alexander, medical director of the campus organization that oversees clinical trials at Stanford, one of the top universities in the world for the number of trials registered with the federal government - nearly 300.

For Harakhchand Savla, 58, taking part in a clinical trial isn't just about extending his life beyond the two years or less that victims of glioblastoma usually have. It's about being a part of something larger.



"A lot of people are trying to understand what cancer is all about, and I think if the vaccine is successful, then it can be a big relief to millions of people," he said. "The picture is much larger than my own cancer."

Stanford's clinical trials cover a range of conditions, from lower back pain and sexual dysfunction to cystic fibrosis and leukemia. It's a little easier to find patients suffering from diseases like cancer because they are more desperate to find effective treatments, but many medical researchers struggle mightily to recruit subjects.

A major challenge is just getting the word out about clinical trials. Another is that some conditions are rare, and the only people who fit the trial profile could be spread around the world.

Stanford Professor Sean Mackey thought it would be easy to find people for a clinical trial on how the drug duloxetine alleviates chronic lower back pain. Lots of people suffer from it, the medication is safe and volunteers are compensated.

But in the last six months, he has recruited just 10 of the 30 people he needs. And he has gone to great lengths, including advertising on Craigslist.

"In pain management, we go through a time-consuming and frustrating process of rotating people through a variety of medications until we find one that works," said Mackey, director of the Stanford Systems, Neuroscience and Pain Lab. "Wouldn't it be nice to find out why the medications work and who they're working for?"

He hopes Stanford's new clinical trials Web site helps people find his study. (Read more about the trial at links.sfgate.com/ZCGT.)

Nona Gamel faces the same hurdle. She initially thought she would have no problem attracting volunteers to her trial on whether changing a person's anti-depressant medication to a different drug would alleviate the common problem of reduced sexual drive.

"We were very, very wrong," said Gamel, a Stanford clinical research manager in psychiatry.

She wonders if it's because her test drug is already on the market and patients can just ask their

doctors for it. Or maybe it's because they don't realize their lack of sexual desire is connected to their antidepressants. Or maybe people are just too busy.

She does know that over the last six years, it has become harder to recruit for psychiatry trials. Gamel has tried Craigslist, newspaper and radio ads and postings on telephone poles and kiosks. The Internet pop-up ad yielded nothing.

She said "I'm ashamed to admit" she once even stuffed flyers under windshield wipers for a clinical trial on general anxiety.

The new Web site is something that "some of us have been begging for," she said. (Read more about her study at links.sfgate.com/ZCGU.)

Gamel believes doctors, often well aware of clinical trials, sometimes are reluctant to suggest patients take part because they could end up getting a placebo instead of treatment. She fears many clinical trials will go overseas, where it's easier to recruit subjects but harder for researchers to maintain control.

Stanford's new Web site might be a crucial marketing tool, but it stems from a larger movement to create transparency in clinical trials nationwide. In the past, researchers didn't have to register trials, which made it easier to hide negative results, like the now-infamous ones in which adolescents who took certain antidepressants were more likely to commit suicide.

In 2005, the International Committee of Medical Journal Editors began requiring researchers to register their trials on clinicaltrials.gov before enrolling patients if they hoped to publish in a reputable journal.

Colleen Fitzsimmons, a clinical research coordinator at Stanford, knows firsthand the value of clinical trials. Her mother lived seven more good years because her physician knew of promising clinical research at Stanford on a cancer drug he prescribed for her. Now Fitzsimmons is doing clinical research at Stanford on a drug that could stave off the return of ovarian cancer for more than five years. She needs seven to 15 ovarian cancer patients who have had surgery and chemotherapy. The research will ultimately involve 870 women at 120 hospitals in the United States and Europe. (Read more about her study at links.sfgate.com/ZCGV.)

Her first patient, Cheryl Byrne of Clovis (Fresno County), learned of the trial from a friend in Washington state. Now Byrne must make the long drive to Stanford at least once a month for up to two years. Without any intervention, the cancer is likely to return in two to eight months.

"(Even) if I got into the placebo group, I would be no worse than I was," Byrne said. "Driving three hours up and back: That's a small price to pay if this works out."

Many researchers think if more people simply knew about clinical trials, they would enroll. Gamel has taken part in arthritis studies.

"I wonder if the general public realizes if they have any kind of problem they could maybe participate in a clinical trial. There's a huge social benefit," she said. "If you're suffering from something, you have a stake in hoping some new and better drugs are developed."

To find the trials

Master site: To find most registered clinical trials, check out clinicaltrials.gov.

Background: To learn more about clinical trials, from the lingo to the protocols, go to www.trialscentral.org.

Many universities also have their own sites, such as:

Stanford University: med.stanford.edu/clinicaltrials

UCSF: www.ucsfhealth.org/adult/health_library/trials.html

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