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Life and leisure
in Central New York

A CASE FOR Patient Advocacy

Trisha Torrey turns misdiagnosis into opportunity to help others

By Amber Smith
Staff writer

What would you do if a doctor told you one summer day that you had a rare cancer and without chemotherapy you would be dead by Christmas?

Trisha Torrey is glad for all the things she *didn't* do.

The Syracuse woman didn't blow all her money on the vacation of a lifetime. She didn't think her diagnosis was a death sentence. Though paralyzed emotionally, she didn't give up hope. She didn't stop asking questions of her doctors: "Is chemotherapy my only option?" and "How do you

know I have cancer?"

What Torrey did do is keep playing golf.

She felt fine. She didn't have the fever and chills, weight loss and malaise described by most people with her type of cancer.

"I'm out here playing the best golf I have in years. How can I need chemo?" she asked. "It didn't add up."

That niggling suspicion helped move Torrey from grim cancer diagnosis to spirited health advocacy. She says her experience illustrates the importance of patients taking responsibility for their health care and the evolution of the doctor-patient relationship

— from reverence for the doctor to health-care partner. Torrey says that suits aging baby boomers who are more educated and who have better access to medical information via the Internet than previous generations.

"I never set out to prove I didn't have cancer," says Torrey, 53, a poised marketing consultant who specializes in Web site marketing and development. She set out to find alternatives to chemotherapy, which from all she read was not very effective in treating subcutaneous panniculitis-like T-cell lymphoma, a cancer that affects the cells of the lymphatic system throughout the body. The day she was scheduled to start chemotherapy she

got a second opinion. What she ultimately discovered was that she didn't have cancer, but an inflamed cluster of cells — called panniculitis — that looked like cancer under a microscope.

Torrey's oncologist, Dr. Jeffrey Kirshner, admits "it's not that uncommon to have a questionable diagnosis, particularly if you're dealing with a rare diagnosis." Tumors of the lymphoid tissue called lymphomas, particularly, can be tricky. "It's not always black and white. Sometimes there are borderline changes that could be pre-malignant. Sometimes there are benign conditions that could resemble a malignancy," he says.

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DIRE DIAGNOSIS?

If you're facing a dire diagnosis, Trisha Torrey suggests:

- Find a doctor** who is willing to partner with you.
- View doctor** appointments and tests as opportunities to learn about your condition.
- Ask** questions until you're satisfied they have been answered.
- Recognize** that no doctor, no matter how informed or skilled, knows everything about every disease.
- Don't be** afraid to get a second or third opinion.
- Network.** Talk to everyone about your situation; you'll be amazed at who can help you.
- Learn your** options, and the advantages and disadvantages of each.
- Distinguish** between wishful thinking and intuition. Wishing you don't have a particular diagnosis can lead to denial, which is counterproductive. You have nothing to lose by trusting an intuition that says you might not have the disease, if you seek and listen to medical advice.

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HOW IT HAPPENED

Syracusan Trisha Torrey got a cancer diagnosis in July 2004 that she learned, in September, was false. A timeline of her experiences follows:



