



## WEB EXCLUSIVES

# Playing the Numbers Game

BY LINDSAY RAY

*Ovarian cancer survivors ponder implications of CA-125 study.*

Numbers can play an intrinsic role in our lives: credit scores, calorie counts, anniversary dates, or paychecks. For most ovarian cancer survivors, one number stands out above the rest—their CA-125 levels, a measure of a protein that can signal ovarian cancer recurrence.

“I know that a majority of ovarian cancer patients live for their next CA-125 results, ... so no matter how we counsel them regarding the value of CA-125 testing and the limitations to that, over time they still tend to live and die by the numbers,” says Carolyn Muller, MD, director of gynecologic oncology at the University of New Mexico Health Sciences Center. However, the value of this number has come under recent fire.

This past summer, a European study presented at the American Society of Clinical Oncology annual meeting concluded that overall survival did not improve in patients who had initial surgery and chemotherapy treatment and then received treatment after their CA-125 rose to a certain level when compared with patients who delayed treatment until physical symptoms occurred (bloating, pelvic or abdominal pain, urinary frequency or urgency, and difficulty eating or feeling full quickly). Furthermore, patients who did undergo earlier treatment experienced more anxiety and a lower quality of life, presumably from treatment side effects since they received treatment earlier and more treatment overall. (Read more about the study in [“CA-125 Monitoring Not Helpful for Ovarian Cancer Survivors.”](#))

“The results of this trial are completely counterintuitive—that early treatment doesn’t necessarily help, but in fact can do more harm,” says lead investigator of the study, Gordon Rustin, MD, of the Mount Vernon Cancer Centre in England. “It’s going to take a lot of time and explanation for people to realize this actually is a benefit to them.”

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—Annie Ellis, ovarian cancer survivor

But survivors, and many U.S. doctors, aren't ready to change their routines just yet.

Annie Ellis, 45, who is currently in her third remission, didn't have physical symptoms when her CA-125 levels became elevated, which led to imaging scans confirming her two recurrences. She considers herself a "CA-125 junkie," and relies on a normal CA-125 reading every six to eight weeks to reassure her that the cancer is in remission. She was particularly interested in the study results, which made headlines around the world.

"I have ovarian cancer, which you know, the stats aren't the greatest. That causes me anxiety," Ellis says. "The CA-125—yes, there's anxiety involved every time I get this pulled, but it's the only thing that gives me any sense of control. It's one piece of information that maybe I could do something with."

"The women's reactions are very, very mixed," says Karen Kaplan, CEO of the Ovarian Cancer National Alliance (OCNA). "A lot of them rely very heavily on the CA-125 just as sort of a check in on how they're doing, and would be terribly, terribly anxious without being able to get it."

Christine Schmidt, a 10-year survivor who lives in Washington, D.C. and acts as president-elect of the Ovarian Cancer National Alliance, believes continued testing should be up to the individual and her oncologist. "I think it's really important that people are very clear about what their needs are and have a good honest discussion with their physician. And that the physician gives the patient really good, honest advice."

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—Karen Kaplan, CEO of the Ovarian Cancer National Alliance

Kaplan agrees, and suggests that the conversation regarding the study be specific to the patient and her cancer. "I would want a personal answer. What about me? What about my cancer and how it fits into all that we know?"

She also suggests asking your oncologist about their thoughts on the study, how definitive this trial was, and the probability of whether early treatment, based on CA-125, for your specific cancer could stop the disease from growing. Ask your physician if you could be an exception to the statistic.

CA-125 may still continue to be an important number for ovarian cancer survivors, but the recent study may give women the comfort of knowing they won't have to rush straight into treatment if they feel well and have no symptoms, even if their CA-125 levels are on the rise. On the other hand, it may be OK to forgo the testing and the anxiety that accompanies it altogether.

Even before Rustin's study results were announced in late May and after nearly two years with no sign of cancer, Ellis and her doctor made the decision that, if

her next CA-125 test levels are normal and she is comfortable spacing the tests out, they would push back her CA-125 testing to every three months—what Ellis calls a “weaning off” of the test due to her stable CA-125 levels.

“You know, there’s a part of me that’s ready to take this step, and there’s a part me,” she pauses. “I’ve had this number for so long. And this is the first time that it’s stayed in this normal range for so long, that I’m ready to take this step.”

*For more on this topic, watch for Special Report “How Should Ovarian Cancer Survivors Be Monitored for Recurrence?” in the CURE Fall issue.*