



RECENTLY DIAGNOSED

Unexpected Doesn't Mean Untreatable

Women diagnosed with rare, female-only cancers can find a clinical expertise and a positive prognosis.

By Erin Brereton



Many women are aware they should be screened for certain types of cancer—skin cancer, for example, [the most commonly diagnosed cancer](#), and breast cancer, which the [National Cancer Institute](#) suggests the U.S. will see more than 266,000 new cases of in 2018 alone.

A number of women, however, may be largely unfamiliar with some other kinds of cancer that are much rarer—such as gestational trophoblastic disease (GTD), which occurs when cells that grow around a fertilized egg after conception form a mass in the placenta.

GTD accounts for less than one percent of all gynecological cancers, according to the [American Society of Clinical Oncology](#); and, much like the cancer itself, one of the ways GTD can manifest is also extremely uncommon, according to [Julian Schink, MD](#), chief of gynecologic oncology at Cancer Treatment Centers of America® (CTCA) and medical director of gynecologic and medical oncology at CTCA® in Zion, Illinois.

“Sometimes it presents as a miscarriage; that’s a relatively benign variance,” Schink says. “If it otherwise presents as widely metastasized cancer called choriocarcinoma, that’s very rare.”

Vulvar cancer is another infrequently seen condition, according to [Natalie Godbee, DO](#), a gynecologic oncologist at CTCA in Goodyear, Arizona. The condition comprises just 0.4 percent of all new cancer cases in the U.S. each year, according to the [National Cancer Institute](#).

“Vulvar cancer is becoming more frequent in younger women due to an increase in HPV infections,” Godbee says. “[But it’s] not common.”

Knowledge is Power

Being diagnosed with a rare type of cancer can be challenging for patients, according to Schink, because they may not be familiar with the condition—or initially know where to turn to learn more about it.

“A patient with breast cancer probably has a friend or someone in their network who has had it; they have people to talk to about it,” he says. “With these rare cancers, that network doesn’t exist.”

Support groups, however, have formed in some areas for patients who have been diagnosed with rare types of cancer; physicians can also provide helpful information.

“Most patients are unaware of these cancer types and require education about the disease,” Godbee says. “Once patients are educated about the tumor type, treatment and prognosis, they have a different mindset. [Vulvar cancer and GTD] are usually found in the early stage and have good prognosis.”

Atypical, But Not More Aggressive

In addition to finding out more information, it’s important for patients to understand being diagnosed with a cancer that’s considered to be somewhat uncommon doesn’t automatically imply medical care won’t be an option.

“Just because a cancer is rare doesn’t mean it’s untreatable,” Schink says. “Gestational trophoblastic disease is super rare, but also super treatable.” Choriocarcinoma has a [90 to 95 percent](#) cure rate; that cancer only occurs in [2 to 7 out of 100,000 pregnancies](#).

Consider granulosa cell ovarian cancer, which represents roughly one to two percent of all ovarian cancers. Although irregular bleeding in between periods can be a sign the tumors are present, the condition is typically asymptomatic, according to Schink; diagnosis often occurs when a patient has surgery to remove a mass that was spotted on an ultrasound.

Although the diagnosis may come as a surprise to patients, the cancer is very slow-growing, Schink says; in addition, it bears a unique, very sensitive marker that physicians can follow to help identify a reoccurrence long before it would typically be found clinically.

“When you say something is rare, it undermines [patients’] confidence because it makes people think, ‘Nobody knows what to do about it’—that isn’t necessarily true at all,” he says. “The reality is, if you have a rare cancer, it’s really important to seek out an expert who has experience managing that particular cancer. One of the reasons people go to CTCA is because they are far more likely to encounter people who have a lot of experience with rare tumors.”

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