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Until There's a Cure – Frequently Asked Questions

Is OCRA putting funding toward developing an early detection test?

In order to develop an effective early detection test for ovarian cancer, we still have much work to do to better help understand how ovarian cancer develops and spreads. Researchers are working to better understand the origins of the disease (such as discovering that lesions have been found on the fallopian tubes in ovarian cancer patients) and where else in the female reproductive tract these precancerous cells, that will later form tumors in the ovaries, might present. OCRA has invested heavily in this type of research, and continues to do so. But this learning takes time — it could take decades – and so scientists are also focused on discovering better treatments for those who need effective therapies today (something we are also investing in).

While we are making great strides in gaining this knowledge, as well as improving treatment options, we must do what we know works in preventing people from getting ovarian cancer in the first place.

What about promoting CA-125 tests?

CA-125 is a biomarker, a protein called Cancer Antigen 125, that may be elevated in the blood of those with ovarian cancer. As a tool for ovarian cancer detection (or screening), it is not perfect – CA-125 is also often elevated in the blood of people with endometriosis, fibroids, liver cirrhosis, and who are pregnant (just to name a few conditions). Furthermore, it misses about half of actual ovarian cancer cases, and therefore ovarian cancer screening guidelines do not recommend the CA-125 blood test as a screening tool in the general population. When doctors suspect ovarian cancer, they often measure CA-125 levels in their patients, but the test is just one of the tools in the doctor's toolbox. CA-125 is FDA approved for assessing treatment effectiveness after diagnosis, as well as monitoring for recurrence.

The only way to definitively diagnose ovarian cancer is through surgery. And since CA-125 levels are often elevated for any number of reasons, using that blood test as a screening tool would send otherwise healthy people into unnecessary surgery. In fact, this could cause more harm (both emotional and physical) to more people than it would save lives, as the exploratory surgery itself comes with risk.

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What efforts are being made for rare ovarian cancers that are not caused by genetic mutations?

OCRA has invested more than $110 million into the research that leads to better understandings of *all* types of ovarian cancer, and better outcomes for everyone impacted by the disease. In fact, this year alone, we are funding nearly $7M in grants, the largest annual investment to date. OCRA researchers are working tirelessly toward learning more about the origins of the disease, the biological mechanisms that affect tumor growth, and immunological responses. Some of this involves known genetic mutations (such as BRCA 1 and 2, and lesser common mutations often found associated with rare ovarian cancer types such as STK11 and DICER1), and some of this research may discover new mutations that could be the cause of other subtypes of the disease.

Furthermore, these investigators are looking beyond the ovaries, gaining new understandings of how other parts of the female reproductive tract impact tumor growth in the ovaries. Just as we now know that the most common and lethal form of ovarian cancer begins in the fallopian tubes, researchers believe that some subtypes of ovarian cancer arise in the endometrium. And of course, we are funding researchers who are working to improve treatment options.

But while all of this is happening, while we are investing in the research that will improve outcomes for everyone facing an ovarian cancer diagnosis, we would be derelict in our duties if we did not *also* do everything we can to prevent people from getting this disease in the first place.

What does genetics have to do with ovarian cancer?

There is a very strong connection between inherited genetic mutations and ovarian cancer. Here is what science tells us:

- Ovarian cancer is considered a rare disease, with the average lifetime risk for being diagnosed only 1-2%. But for those with a family history and/or genetic mutation, that risk level can jump to 40-50%.

- Nearly 20% of ovarian cancer patients have an inherited genetic mutation that was likely the cause of their disease. This is one of the highest percentages of inherited mutations among any cancer.

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For this reason, OCRA — along with support from the Society of Gynecologic Oncology — strongly encourages everyone to know their family history, and if applicable, get genetic testing. Knowledge is power, and those with an elevated risk can take preventative measures.

How will this help people who don't have a genetic mutation?

We believe knowledge is power. Those who find that they have a genetic mutation that dramatically increases their risk for developing ovarian cancer may feel shock or fear. But they can discuss this with their doctor, and learn more about a prophylactic surgery that may greatly reduce their risk. On the other hand, those who discover they *don't* have a genetic mutation may feel a sense of relief and a weight off their shoulders. This doesn't mean their risk for getting ovarian cancer is zero; a large percentage of the most common and lethal form of ovarian cancer arises in people with no genetic mutations. This is why many doctors are encouraging those, regardless of their level of risk, who are having a planned pelvic surgery to consider removing their fallopian tubes at that time (known as opportunistic salpingectomy). Studies are showing this to be a safe and effective procedure that can save lives.

What about screening/early detection?

Screening is a procedure done in the general population, like a colonoscopy or Pap smear, that looks for pre-cancerous cells, cysts or lesions. Screening looks for irregularities before cancer has a chance to grow, in order to prevent disease. Early detection, on the other hand, is a method of finding cancer in its earliest stages, when intervention can be successful and may help prevent mortality. Mammograms are a well-known early detection tool for breast cancer.

There is no screening or early detection test for ovarian cancer. Some people think the Pap smear can detect ovarian cancer, but it cannot. It can only screen for cervical cancer. This is one of the reasons why ovarian cancer is the deadliest of all gynecologic cancers; symptoms typically only appear, and thus ovarian cancer is often only diagnosed, when the disease is in late stages and the cancer has spread.

When experts in the field of ovarian cancer talk about early detection, they are working to better understand the origins of the disease (such as discovering that lesions have been found on the fallopian tubes in ovarian cancer patients) and where else in the female reproductive tract these precancerous cells, that will later form tumors in the ovaries, might present. But this type of

learning takes time — it could take decades – and so scientists are also focused on discovering better treatments for those who need effective therapies today.

Shouldn't we be promoting symptom awareness since early detection can save lives?

There is tremendous effort within the ovarian cancer community to share information about signs and symptoms, which are often confused with other conditions. It is important that individuals and healthcare providers are aware of these symptoms, because knowing them can aid in getting an earlier diagnosis and perhaps make treatment a bit easier. Also, correctly identifying the symptoms of ovarian cancer can help patients receive earlier care from a gynecologic oncologist, which has shown to improve outcomes.

However, a recent long-range study has shown that earlier detection of ovarian cancer using currently available methods, does not reduce mortality. This seems counterintuitive, but scientists studied 200,000 women over a period of 35 years to determine the effectiveness of screening using the CA-125 blood test and transvaginal ultrasounds (TVUS). While they did see some stage shifts (more diagnoses of earlier stage disease), they did not see a change in mortality. Doctors and scientists are speculating as to why this is so, and suspect it may be because some ovarian cancers — even within the same subtype — are just more inherently aggressive than others.

So, while it is still important to know the symptoms of ovarian cancer, to say that having this knowledge will save lives is untrue. And it can be harmful as it places the blame on the patient who, for any number of reasons, may not have recognized the symptoms when they first began. It also dilutes energy and resources away from critical research, such as better understanding of disease origins and precision treatment.

What about blood tests that screen for many types of cancer including ovarian cancer?

There is much in the news about multi-cancer blood tests that claim to screen for a variety of cancers. While there may be data to support their effectiveness for other cancers, there is no data that shows these tests to be effective at reducing mortality for ovarian cancer. (We wish it were that easy!) Until there are rigorous studies supporting any screening, treatment or prevention method, along with FDA approval as appropriate, we cannot promote it.

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Do the prevention strategies work for endometrial or uterine cancer?

We do know that a family history of endometrial (or uterine) cancer (along with breast, ovarian and colon) can put someone at increased risk for ovarian cancer. As to whether prophylactic removal of one's fallopian tubes reduces the risk for endometrial/uterine cancer, that has not been indicated. However, studies have shown that the use of combination oral contraceptives (with estrogen and progesterone) can lower the risk of endometrial cancer, as well as ovarian cancer. And progesterone IUDs also reduce risk for endometrial cancer. It is important to note that just like ovarian cancer, endometrial cancer is an umbrella term that includes subtypes, each with varying points of origin, treatment methods and disease trajectories.