Ovarian cancer: It's time for change

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In collaboration with the South Georgian Bay Community Health Centre

* Disclaimers *

- 1. While I am an employee of Ovarian Cancer Canada, this educational session and all activities related to the Run for Her is outside of my official work and I am not speaking on behalf of Ovarian Cancer Canada
- 2. None of the information presented is meant to serve as medical advice. If you are concerned that you may have, or may be at risk for, ovarian cancer please speak to your doctor or visit ovariancanada.org
- 3. While I use the term "women" throughout this presentation, not all people with ovaries and therefore at risk for ovarian cancer are women

* A dedication *

This session is dedicated to all of the strong, resilient, selfless, passionate women I have the privilege of working with as part of Ovarian Cancer Canada's Patient Partners in Research program. Your stories and experiences are what drive me to keep pushing forward.

Overview

	The Science (Alicia)	A patient perspective (Shannon)
Ovarian cancer 101	\checkmark	\checkmark
Early detection	\checkmark	\checkmark
Risk & prevention	\checkmark	\checkmark
Gaps & inequities	\checkmark	\checkmark
Time for change	\checkmark	\checkmark

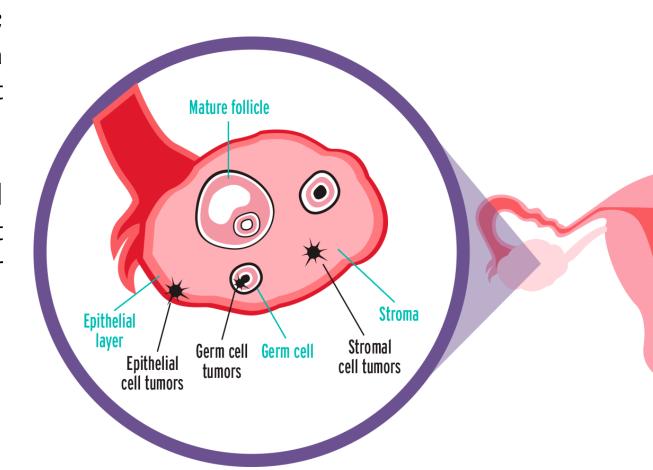
Ovarian cancer: the hard facts

- Ovarian cancer is the 5th most common cause of cancer deaths in Canadian women
- ~3,000 Canadian women are diagnosed with ovarian cancer every year
- 5 Canadian women die from ovarian cancer every day
- * 55% of women diagnosed with ovarian cancer die within 5 years
- Long-term survival outcomes for women with ovarian cancer have not changed in
 50 years

Ovarian cancer: it's complicated

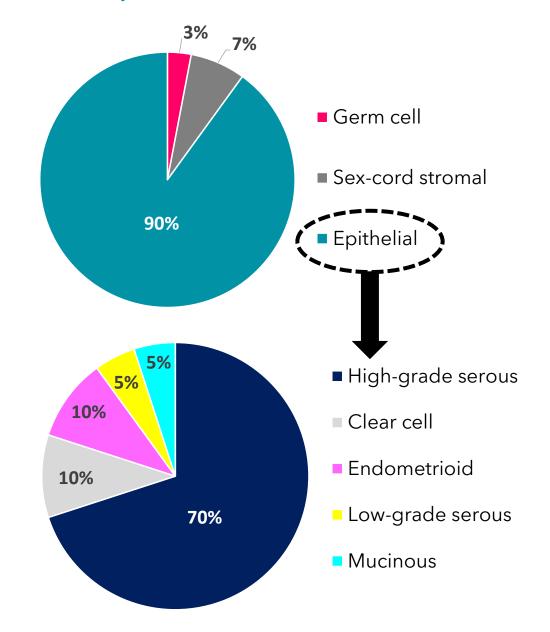
Ovarian cancer is not just one disease; rather the term "ovarian cancer" refers to a group of distinct cancers that originate at or near the ovaries.

Ovarian cancers can be broadly classified according to which kind of cells they start from (e.g., epithelial cells, germ cells or sex-cord stromal cells).

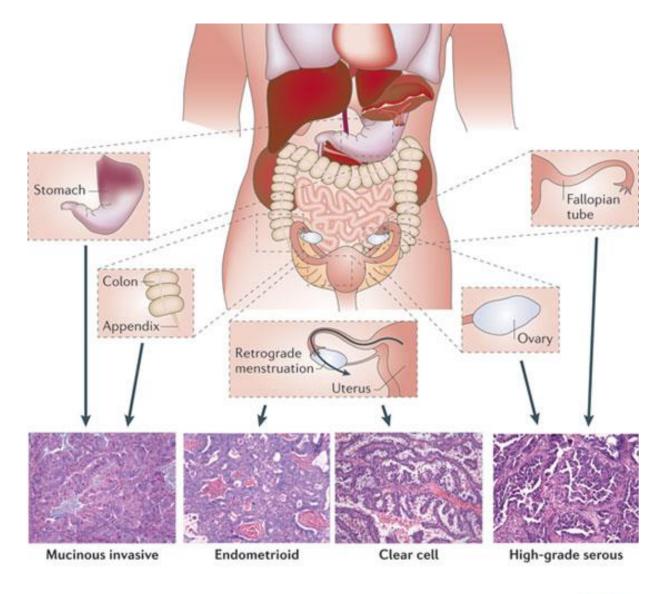


Ovarian cancer: it's complicated

Each of these categories can be further divided into different types, each associated with different precursor lesions, risk factors, typical stage at diagnosis, response to treatment and prognosis.

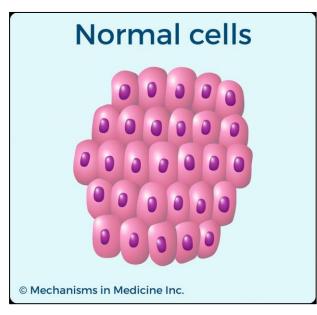


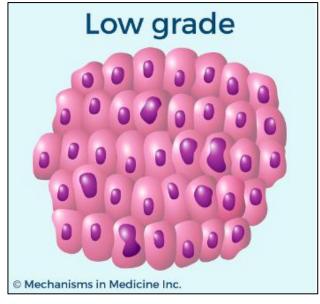
Not all "ovarian" cancers start in the ovary

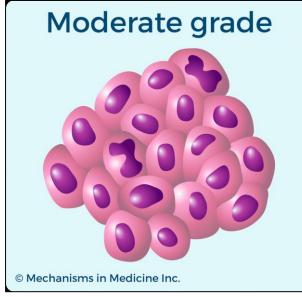


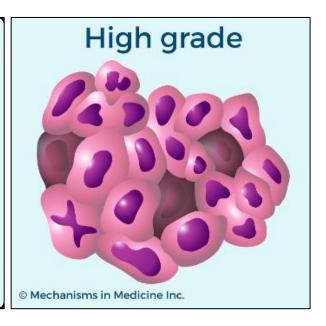
The majority of cases of the most common type of ovarian cancer actually start in the fallopian tube

"Grade" refers to what tumour cells look like under a microscope





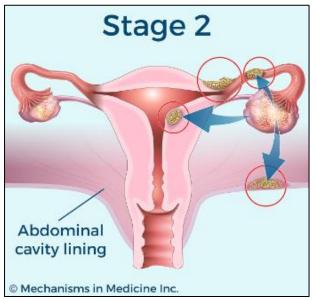


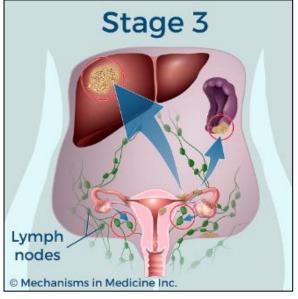


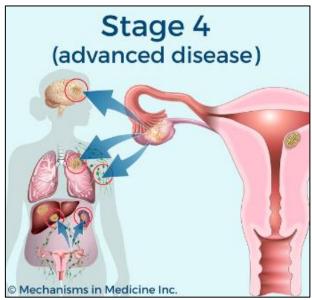
Grade 1 Grade 2 Grade 3

"Stage" refers to how far the cancer has spread in the body









Unfortunately, 75% of women with ovarian cancer are diagnosed in stage 3 or 4

How is ovarian cancer diagnosed?

 Many women with ovarian cancer report experiencing one or more of the following symptoms:



Less common symptoms:

- Changes in bowel habits
- Menstrual irregularities
- Bleeding after menopause
- Unexplained weight gain or loss
- Extreme/persistent fatigue
- Pain with intercourse
- Even if you have <u>all</u> of these symptoms, it does not mean you have ovarian cancer
- However, it is important to talk to your doctor if a symptom is new to you and persists for 3 weeks or more, to rule it out

How is ovarian cancer diagnosed?

2. The following tests can be performed to determine the <u>possibility</u> that you have ovarian cancer:

Transvaginal ultrasound

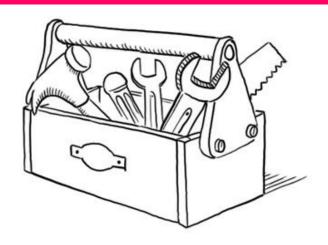
- Ultrasound probe inserted into vagina
- Allows imaging of ovaries and surrounding area to identify structural changes that could be indicative of possible ovarian cancer
- ❖ BUT difficult to detect small cancers

Full pelvic exam

- Doctor will touch the outside of your abdomen to feel for masses
- Then, with fingers inside the vagina and rectum, to try to feel your ovaries from the inside

CA125 blood test

- ❖ Detects a protein called CA-125 (cancer antigen 125) that is released into the bloodstream by cancer cells; an elevated level of CA-125 <u>may</u> be indicative of possible ovarian cancer
- ❖ BUT CA125 can be elevated by benign conditions unrelated to ovarian cancer

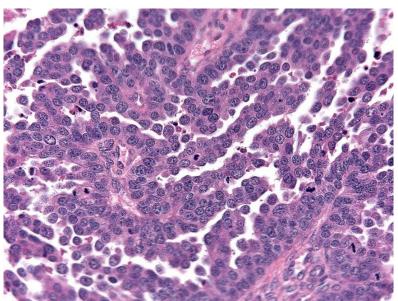


How is ovarian cancer diagnosed?

3. If ovarian cancer is suspected based on the results of these tests, your doctor should refer you to a gynecologic oncologist for diagnosis through surgery or biopsy. Surgery <u>must</u> be performed by a gynecologic oncologist, as these doctors are specialized in ovarian cancer.



4. Another kind of specialized doctor (pathologist) will then look at the tissue from the surgery or biopsy to determine the type, grade and stage of the cancer.



How is ovarian cancer (typically) treated?

In general, treatment plans are based on:

- Cancer type, stage and grade
- Your age and general health
- Whether the cancer has just been diagnosed or has recurred

Surgery

- Removal of as much cancer as possible
- Also used to determine how far cancer has spread

Chemotherapy ("chemo")

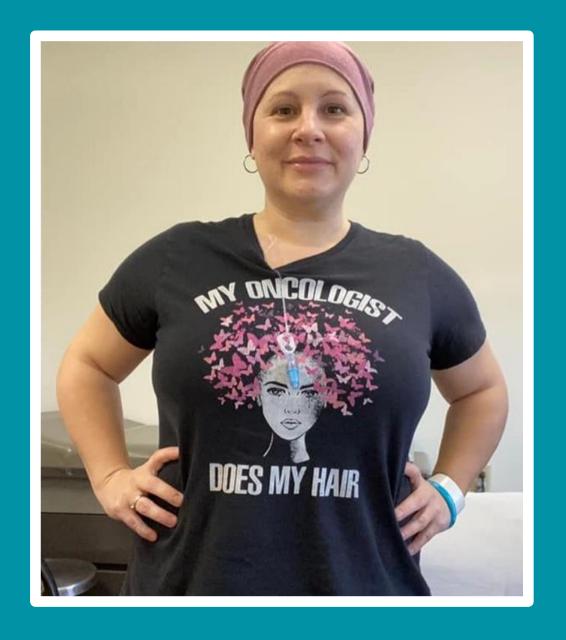
- Using chemicals to kill cancer cells
- Systemic (throughout body)
- Typically a combination of two types of chemotherapy (platinum + taxol)
- Given either before or after surgery

Radiation

Localized, very high dose of radiation to destroy cancer cells

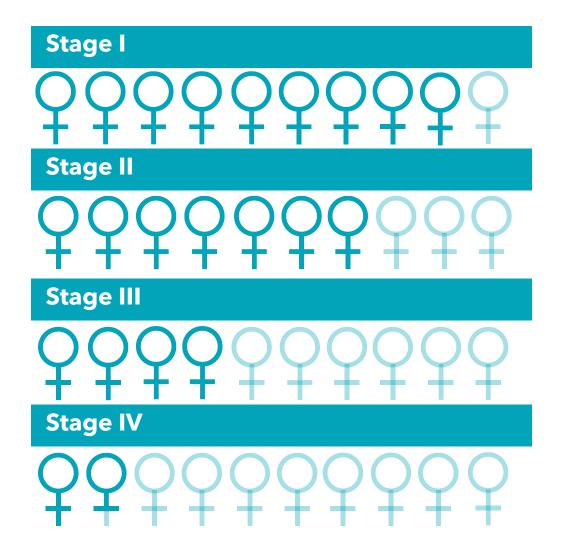
Medications to treat ovarian cancer or prevent recurrence

- PARP inhibitors stops ability of cancer cells to repair DNA damage
- Angiogenesis inhibitors stops ability of cancer cells to make new blood vessels needed for cancer growth



Shannon:
An unexpected diagnosis

Survival by ovarian cancer stage

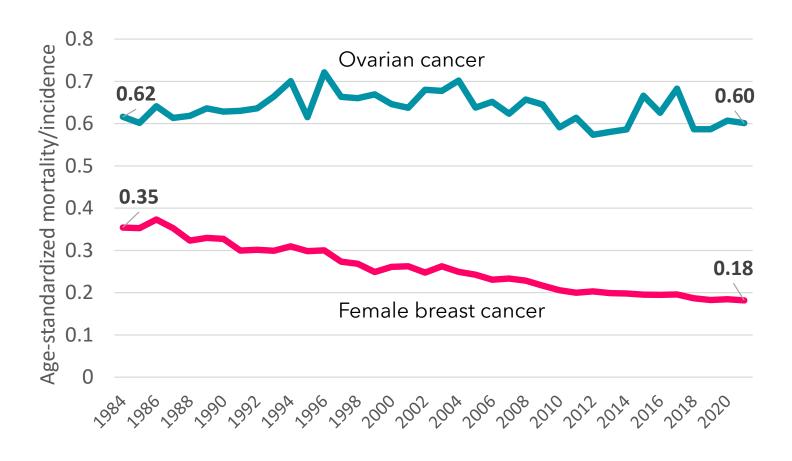


= 10% probability of being alive 5 years after diagnosis of epithelial ovarian cancer

Cautionary note: survival statistics are based on the experience of groups of women and cannot be used to predict a particular woman's chances of survival

The survival paradox

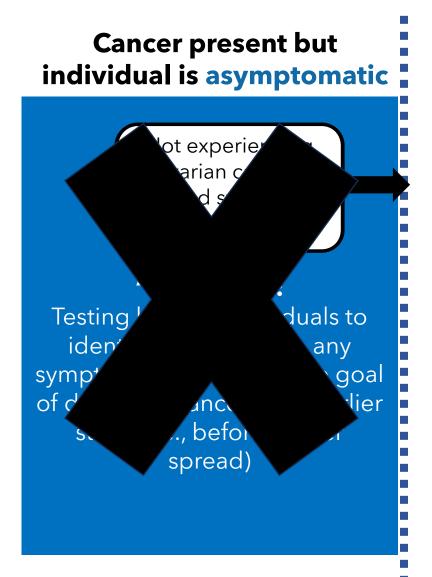
While many individual patients are living longer and better with treatment advances (i.e., better short-term survival), long-term survival rates for ovarian cancer as a whole have not changed in 50 years.



Why is it so hard to detect ovarian cancer at an early stage?

- Symptoms are non-specific
- No reliable screening method
- Most common type spreads when cancer is still very small, before symptoms appear

The two components of early detection = screening and early diagnosis



Screening using transvaginal ultrasound and CA125 testing **does not save lives**

Tests do not detect ovarian cancer <u>early</u> <u>enough</u>, in a <u>big enough proportion</u> of patients to reduce the number of deaths from ovarian cancer



A Pap test (cervical smear test) does NOT detect ovarian cancer.





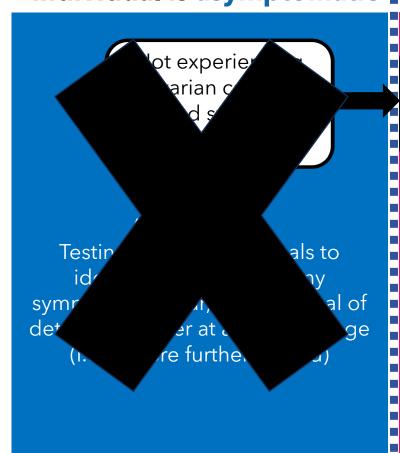
Towards the next generation of ovarian cancer screening

- Researchers across the globe are working on designing and testing better ways to screen for ovarian cancer
- Compared to 20-30 years ago:
 - Better understanding of ovarian cancer biology
 - ✓ Much more sophisticated and sensitive technologies
- This will allow us to identify cancers when they are much smaller, with the hopes that they can be detected early enough to impact survival

The two components of early detection = screening and early diagnosis

Cancer present but individual is asymptomatic

Cancer present + individual is symptomatic



Experiencing 1 or more ovarian cancer-related symptoms

"Symptom
awareness":
knowing that
certain symptoms
(when new +
persistent) may
indicate the
possibility of
ovarian cancer

Consults healthcare provider about symptoms ("initial presentation")

Diagnosed with ovarian cancer

"Early diagnosis":

Diagnosing symptomatic patients as quickly as possible (i.e., shorter time to diagnosis from the time of initial presentation), to initiate treatment

Symptom awareness and early diagnosis

Early diagnosis depends on two factors:

- 1) Women who are experiencing persistent/concerning ovarian cancer-related symptoms consult a healthcare provider
- 2) Healthcare providers respond to these concerns appropriately, through ordering of appropriate tests and/or referral to secondary care

Overall, symptom awareness does not lead to improved survival

BUT getting to a diagnosis quicker allows:

- ✓ More time to get appropriate referrals to specialists
- ✓ An easier course of treatment if surgery and chemotherapy occur before a patient is very sick
- ✓ Less complicated surgery
- ✓ Easing of psychological stress from delayed diagnosis



Shannon: the importance of self-advocacy

Who is at risk for ovarian cancer?

- Anyone born with ovaries is at some risk for ovarian cancer
- ❖ In the absence of other risk factors, there is a 1 in 70 chance that someone will develop ovarian cancer in their lifetime ("average risk")

Prevention in average risk population

If you are average risk for ovarian cancer, it's recommended that you speak with your healthcare provider about removing your <u>fallopian tubes</u> if you're already planning gynecologic surgery (e.g., hysterectomy or tubal ligation) and are done having kids ("opportunistic salpingectomy")





To Prevent Cancer, More Women Should Consider Removing Fallopian Tubes, Experts Say



White Coat, Black Art · THE DOSE

What experts say you should know about ovarian cancer









Electively removing your fallopian tubes can help reduce your risk for the disease



Stephanie Dubois · CBC News · Posted: Feb 11, 2023 4:00 AM EST | Last Updated: 9 hours ago

Who is at risk for ovarian cancer?

Some individuals are at a much higher risk for ovarian cancer:

Increases risk:

- Inheritance of a change in a hereditary cancer gene (e.g., BRCA1/2)
- Family history of specific cancers
- Ashkenazi Jewish or French-Canadian ancestry
- Personal history of breast cancer
- Endometriosis
- Increasing age

Decreases risk:

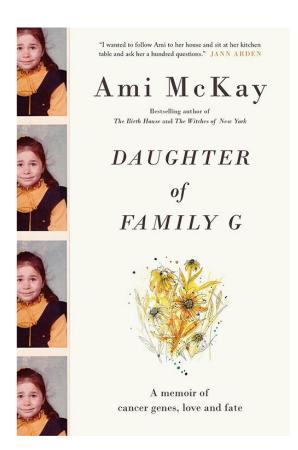
- Removal of ovaries and/or fallopian tubes
- Oral contraceptive pills
- Tubal ligation ("tying tubes")
- Giving birth
- Breast feeding

Hereditary risk for ovarian cancer

- About 1 in 5 ovarian cancers are associated with inherited changes (mutations) in a small number of genes
- These mutations "run in families" and can increase the risk of developing ovarian and other cancers during your lifetime, compared to the general population
- Mutations can be inherited from either the mother or father's side



BRCA1 / BRCA2 1 in 300 women ~15% of ovarian cancer (high-grade serous)



Lynch Syndrome ~1% of ovarian cancer (non-serous)

If you are worried about your risk for ovarian cancer, ask your doctor to refer you to a genetic counsellor.

www.ontariohealth.ca



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Home > Genetics Clinics in Ontario

Genetics Clinics in Ontario

Clinical genetics services are available at clinics across Ontario. This directory for patients and health care providers lists genetics clinic locations, services and the types of patients served.

Refine

Areas of Care

- ☐ Adult Genetics (12)
- ☐ Biochemical Genetics (5)
- □ Cardiogenetics (13)
- ☐ General Genetics (15)
- \square IVF & ART, Preimplantation Genetic

Testing (3)

Show more

Location

- ☐ Hamilton (1)
- ☐ Kingston (1)
- ☐ Kitchener (1)
- □ London (1)
- ☐ Mississauga (1)

Show more

Population Served

- ☐ Adults (21)
- □ Children (17)

Accepts Self-Referrals

- □ No (20)
- ☐ Yes (3)

Displaying Results

23 Results

Bhalwani Familial Cancer Clinic, Princess Margaret Cancer Centre

Population Served: Adults

Area of Care: Cancer Genetics

Website: https://www.uhn.ca/PrincessMargaret/Clinics/Familial_Breast... ☐

Cancer Centre of Southeastern Ontario, Kingston Health Sciences Centre

Population Served: Adults, Children **Area of Care:** Cancer Genetics

Website: https://kingstonhsc.ca/cancer-care/genetics-familial-oncolo... ば

Cancer Genetics and High Risk Program, Sunnybrook Odette Cancer Centre

Population Served: Adults **Area of Care:** Cancer Genetics

Website: https://sunnybrook.ca/content/?page=occ-cancer-genetics ば

Genes associated with increased risk for ovarian cancer

Gene/s	Estimated risk for ovarian cancer	Additional cancer risk
BRCA1	39-44% by age 70	Breast, pancreatic
BRCA2	11-18% by age 70	Breast, pancreatic, prostate
MSH2, MLH1, MSH6, PMS2, EPCAM	~10-20% by age 70	Colorectal, endometrial (lining of uterus), gastric, kidney, bladder, small bowel, pancreatic; "Lynch Syndrome"
RAD51C, RAD51D	~11-13% by age 80	
BRIP1	~6% by age 80	

Prevention in high-risk population

- Women with an inherited mutation in an ovarian cancer risk gene ("previvors") are recommended to undergo surgical removal of <u>ovaries and fallopian tubes</u>
- Doctors follow guidelines to determine the best age for a woman to have surgery if she chooses this option

Gene/s	Estimated risk for ovarian cancer	Recommended age for preventative surgery
BRCA1	39-44% by age 70	35-40 years
BRCA2	11-18% by age 70	40-45 years
MSH2, MLH1, MSH6, PMS2, EPCAM	~10-20% by age 70	Timing individualized
RAD51C, RAD51D	~11-13% by age 80	Consider at 45-50 years
BRIP1	~6% by age 80	Consider at 45-50 years

Prevention in high-risk population

1) Identify individuals who <u>may</u> be at increased risk for OC

- ✓ <u>Inherited mutation</u> in an OC risk gene in a close relative
- ✓ Family history of ovarian or other cancers such as breast, endometrial, colorectal, pancreatic or prostate on either side of the family
- ✓ <u>Personal history</u> of breast cancer
- ✓ Belonging to a specific <u>ethnic</u> <u>community</u> (e.g., Ashkenazi Jewish or French-Canadian) associated with higher prevalence of mutations in OC risk genes

2) <u>Confirm</u> increased OC risk through genetic testing

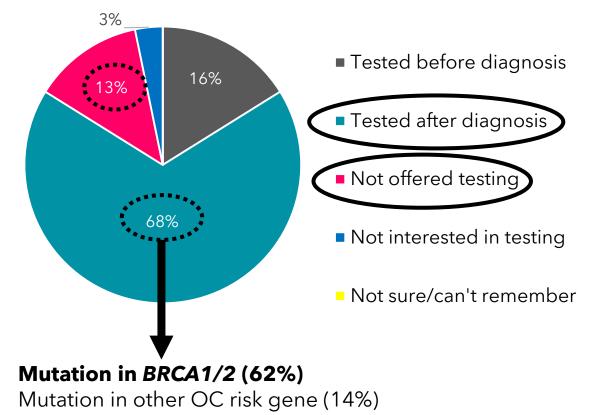
- ✓ Timely referral to <u>genetic</u> <u>counselling</u>
- ✓ <u>Genetic testing</u> of hereditary cancer genes, if appropriate

3) Reduce OC risk in confirmed "previvors"

- ✓ Timely referral to <u>gynecologic</u> <u>surgeon</u>
- ✓ Pre-surgical consult, <u>risk-reducing surgery</u> and appropriate after-care

Family history matters: missed opportunities for ovarian cancer prevention

Genetic testing among ovarian cancer patients who reported a family history of ovarian cancer in a <u>first-degree relative</u> (e.g., mom, sister)



Ovarian cancer could have been prevented

Even more family members may miss the opportunity to prevent ovarian cancer if a mutation is present but not discovered

Previvors: an underserved population

Lack of programmatic follow-up of high-risk patients in most Canadian jurisdictions, to ensure that previvors are referred to the appropriate specialists or pursue prevention strategies. Individuals are essentially "orphaned" after discovering they are at high risk for cancer



Ovarian Cancer Canada's Prevention Task Force



Ovarian Cancer Canada staff, researchers, clinicians, patients and previvors working together to decrease the incidence of ovarian cancer in Canada, by maximizing opportunities for prevention



Shannon: the power of genetics

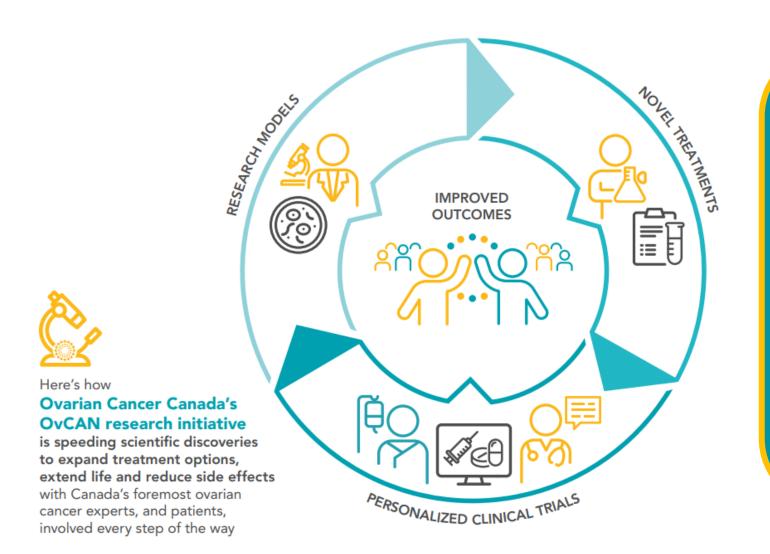
The next big breakthrough in ovarian cancer is around the corner.

Research
is the only way to stop ovarian cancer.





Ovarian Cancer Canada's OvCAN Research Initiative



- 2019-2024
- **♦** \$14M+
- Have funded 44 projects, including 5 clinical trials
- 250 affiliated researchers from across Canada
- 20+ patient partners

Going beyond OvCAN (2024-29)

Innovative, highquality, made-in-Canada scientific research along the ovarian cancer continuum:

- ✓ Prevention
- Diagnosis
- ✓ Treatment
- ✓ Survivorship

Beyond OvCAN is the vision for a sustainable research program for Ovarian Cancer Canada, to ensure that the great work & momentum initiated through OvCAN continues

We are planting the seeds of progress, for a hopeful future:

- $oldsymbol{\psi}$ incidence via prevention
- Ψ late diagnosis
- ↑ equity in care & research
- ↑ quality of life

Communityinformed priorities

- Collaborationcompetition
- ✓ Power of the patient voice
- ✓ National scientific toolbox
- ✓ Social determinants of health
- ✓ Investing in the next generation



Shannon: the power of the patient voice

Want to learn more?

https://www.southgeorgianbaychc.ca

September is Ovarian Cancer Month: What Everyone Should Know about Ovarian Cancer



> September is Ovarian Cancer Month: What Everyone Should Know about Ovarian Cancer

Journal of Family Practice Oncology

How family doctors can help prevent ovarian cancer

Alicia Tone, PhD; Scientific Advisor, Ovarian Cancer Canada atone@ovariancanada.org



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What it feels like: 'A reason to keep fighting' against ovarian cancer

Starla Fiddler uses her "borrowed time" to advocate for others, raise awareness and help however she can to end ovarian cancer. "I know that in my lifetime I will never see a cure, as much as I would like to," she says.

by Robin Roberts



Want to help?





100% of funds raised go to Ovarian Cancer Canada (ovariancanada.org), the only national charity dedicated to overcoming the most fatal women's cancer