

# SUBMISSION TO THE HOUSE OF COMMONS STANDING COMMITTEE ON HEALTH

### WOMEN'S HEALTH STUDY

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## SUBMITTED BY OVARIAN CANCER CANADA

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#### INTRODUCTION

Ovarian cancer is the most fatal women's cancer, with a five-year survival rate of only 44%.<sup>1</sup> This means that of the eight women a day who are diagnosed with ovarian cancer in Canada only four will survive five years.

There is no screening test for ovarian cancer and no vaccine to prevent it. Symptoms are nonspecific (e.g., bloating, abdominal pain/discomfort, urinary symptoms, changes in bowel habits) and diagnostic pathways and tools are limited making timely diagnosis extremely challenging. Ovarian cancer is not one disease. In fact, it is several different diseases making the path to scientific discoveries and improved treatments particularly complex.

With very few exceptions, available treatments have not changed significantly since the 1990s. For the 3,100 Canadians diagnosed with ovarian cancer this year, they will be treated with the same methods, surgery and chemotherapy, and unfortunately these methods are not successful in most patients.

Until recently, breast cancer research in Canada has received six times and prostate cancer research over two times the funding that has been invested in ovarian cancer research, despite a comparatively worse prognosis.<sup>2</sup>

It is not surprising that outcomes for ovarian cancer have not improved much in 50 years.

Effective and strategic research investment is a core lever for change and a focus of this submission, but other opportunities for improving Canada's health care systems are highlighted below to help optimize prevention opportunities, reduce time to diagnosis and develop effective treatments to improve patient outcomes.

#### PREVENTING OVARIAN CANCER BEFORE IT STARTS

Given current challenges with early detection and limited treatment options for ovarian cancer, the most effective way to impact incidence and outcomes NOW is through prevention.

<u>For individuals at high risk:</u> It is essential to identify who is at high risk of ovarian cancer and to improve their access to prevention opportunities. Previvors are individuals at high risk of ovarian cancer because of their inheritance of a mutation in a hereditary cancer gene. An estimated one



in five cases of ovarian cancer can be linked to inherited genetic mutations. Known previvors are recommended to undergo a risk-reducing surgery (RRSO), which removes both ovaries and fallopian tubes, reducing the lifetime risk of developing ovarian cancer from 40% to 1.4%.<sup>3,4,5</sup> If all previvors were identified through genetic testing and underwent risk-reducing surgery in accordance with clinical recommendations, hundreds of lives could be saved every year, reducing the impact of ovarian cancer on patients, families, and loved ones, as well as the healthcare system in our country.

Ovarian Cancer Canada's *The Every Woman Study: Canadian Edition*, explored over 500 patientreported experiences of ovarian cancer.<sup>6</sup> Of the respondents who reported a family history of ovarian cancer in a first-degree relative, 68% reported being offered genetic testing <u>after</u> diagnosis and 13% of those diagnosed were <u>not offered genetic testing at all</u>. Therefore, ovarian cancer could have been prevented in 81% of respondents with a family history. Many researchers have noted disparities in access to genetic testing for individuals of Asian or North American Indigenous origin<sup>7</sup> as well as disparities caused by geographical barriers, financial barriers, a lack of awareness that genetic testing is available and a lack of trust in the health system generally or in how personal genetic information will be used specifically.<sup>8,9,10,11</sup>

#### PRIMARY CARE ACCESS IS ESSENTIAL TO TIMELY DIAGNOSIS

Ovarian cancer patients suffer exponentially due to the primary care access crisis as it plays the central role in detecting the disease.

The role of a primary care physician is key in detecting ovarian cancer. Yet, 22% of adults in Canada- more than 6.5 million people- do not have a family doctor.<sup>12</sup> Without a family doctor to consult women are more likely to be diagnosed in emergency rooms when they are more often at late stage, leading to worse outcomes and lower quality of life.<sup>5</sup>

Due to the lack of an effective screening test,<sup>13</sup> a definitive diagnostic test, and non-specific symptoms, diagnosing ovarian cancer at an early stage or even in a timely way is extremely challenging even when patients have a family doctor. Symptoms can be easily dismissed by both patients and doctors and referrals to appropriate tests can be missed. Primary care physicians should order a combination of tests (typically transvaginal ultrasound, full pelvic and CA 125 blood test) for patients presenting with even one persistent ovarian cancer symptom to help find or rule out ovarian cancer. If ovarian cancer is suspected a primary care doctor should refer the



patient to a gynecologic oncologist so a surgical biopsy can be performed to reach a definitive diagnosis.<sup>14</sup>

In Canada, ovarian cancer diagnostic pathways have been developed by some provincial cancer agencies;<sup>14</sup> however, there are no national standards for the optimal pathway or time to an ovarian cancer diagnosis for women presenting with symptoms.

#### LACK OF EFFECTIVE TREATMENTS

Ovarian cancer is challenging and unique and has not seen the same advances as many other cancers in recent years.

Once diagnosed, standard first-line treatment for most ovarian cancer patients remains cytoreductive surgery in combination with platinum- and taxane-based chemotherapy. While most patients respond well to chemotherapy initially, most women are diagnosed in stage three or four and develop resistance, eventually succumbing to their disease. If we want survival outcomes to improve, we must invest in research that will lead to effective treatments.

Traditional research funding mechanisms have not worked for ovarian cancer and have failed to create significant progress. It is not enough to increase funding to ovarian cancer; we must conduct this research differently. A collaborative and targeted approach is required to improve survival outcomes for this particularly complex disease.

In 2019, the Canadian government took bold action and entrusted Ovarian Cancer Canada with an unprecedented \$10 million investment for five years to fund an innovative ovarian cancer research initiative to improve outcomes. This funding was leveraged into an additional \$4.5 million in commitments from the provinces of Nova Scotia and Saskatchewan, as well as not-forprofit research organizations IRICoR and the Cancer Research Society.

While \$14 million is a modest amount for cancer research, Ovarian Cancer Canada has worked closely with the ovarian cancer research community to re-imagine the traditional approach to medical research, to ensure maximum impact of these funding dollars. We used the funding to support research that could benefit the whole ovarian cancer research eco-system, and which was aligned to the collective goals of researchers, rather than focusing on individual researchers' pursuits. We have made decisions together with the research community, choosing projects that



hold early promise and would benefit patients most. By doing so, researchers have continuously built on one another's research, making advancements quicker and more efficiently.

We have:

- Funded <u>25</u> projects on ovarian cancer research models that will set the stage for future discoveries for the diagnosis, prevention, and treatment for all types of ovarian cancer across <u>6</u> provinces.
- Funded <u>13</u> high-quality pre-clinical studies on novel treatment approaches for ovarian cancer, through open competitions with partners (*NB: our partnership with IRICoR on one of these projects culminated in the creation of Epitopea, a spin-off Montreal-based company dedicated to the development of accessible off-the-shelf immune-based cancer treatments.*)
- Funded <u>5</u> early-phase clinical trials with built-in translational studies, including one focused on a rare type of ovarian cancer, through open competitions.
- Launched a targeted competition jointly with Cancer Research Society to fund <u>2</u> translational research projects.
- Created an ovarian cancer research consortium which consists of <u>250+</u> members, including <u>70+</u> clinicians and representation from academic centres in <u>8</u> provinces to date.
- Established a national team of <u>20+</u> Patient Partners in Research from <u>7</u> provinces, with integration of the patient voice in all research activities.
- Provided partial or full funding for <u>75+</u> research personnel.

Beyond advancing scientific and clinical discoveries Ovarian Cancer Canada is working to ensure that research investigates how all people with ovarian cancer in Canada can receive the best care, regardless of their age, sexuality, gender identity, language, Indigeneity, socio-economic circumstances, racial/ethnic background, or where they live. We are now on the cusp of bringing new treatment strategies to women in Canada. Continued - and increased - investment in ovarian cancer research is vital to achieve a future where ovarian cancer is preventable, curable and ultimately eradicated. Canada is fortunate to have an exceptional ovarian cancer research community poised to use this funding to deliver long-awaited changes for those impacted by the deadliest gynecologic cancer.



#### RECOMMENDATIONS

- Prevention: We must maximize and optimize the identification of individuals at increased genetic risk for ovarian cancer, through timely and equitable access to genetic testing to stop ovarian cancer before it starts.
- Timely diagnosis of ovarian cancer: Canadians must have access to primary care physicians, primary health care providers must be well trained and supported in identifying and responding to ovarian cancer symptoms, and national standards for the optimal diagnostic pathway must be established.
- Research: The federal government must continue and increase investment in innovative, highly focused, comprehensive national research programs such as Ovarian Cancer Canada's that propel crucial breakthroughs from the bench to bedside, faster.

#### CONCLUSION

Given the devastating effects ovarian cancer has on the lives of many thousands of Canadians and their families, Ovarian Cancer Canada will not waver in its commitment to research to enhance prevention, treatment and save lives. Women and gender-diverse people across Canada are depending on us to advocate to improve ovarian cancer outcomes across the continuum of care and keep this research moving forward. They are depending on the federal government as well.

We are grateful for the opportunity to represent the needs of our survivor and patient community to this committee and welcome any request to provide additional information or answer any questions.



#### REFERENCES

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<sup>14</sup> Cancer Care Ontario. Ovarian Cancer Diagnosis Pathway Map. Version 2020.01. Ontario Health.