

WORLD OVARIAN CANCER COALITION

2013-2018 ACHIEVEMENT REPORT



WORLD
OVARIAN
CANCER
COALITION

THE
EVERY
WOMAN
STUDY™



WORLD
OVARIAN
CANCER
DAY



INTRODUCTION

Since the launch of the first World Ovarian Cancer Day campaign in 2013 through to the formal establishment of the Coalition in 2016, we have worked tirelessly to raise awareness of ovarian cancer and to shine a light on the global challenges faced by women living with this disease.

By working with our partner organizations from around the world, we have gained insight into the global challenges that have meant that ovarian cancer still has one of the lowest survival rates of all female cancers. By seeking direct input from women living with ovarian cancer about their experiences, we have established a solid evidence base that speaks to the tremendous hurdles that must be overcome to ensure that every woman diagnosed with ovarian cancer has the best possible chance of survival and the best quality of life possible – wherever she may live.

Despite these many challenges, we are optimistic about the future and, most importantly, the opportunity to change the course of this lethal disease. We are enormously proud of what we have achieved since the first meeting of global leaders in 2014 where we considered the possibility of extending global collaboration.

We are especially proud of the formal establishment of the World Ovarian Cancer Coalition as a formal legal entity (2016); the increase in partner organizations that belong to the World Ovarian Cancer Coalition (from 23 in 2013 to nearly 140 in 2018); the ongoing success of World Ovarian Cancer Day and the more recent publication of our groundbreaking World Ovarian Cancer Coalition Every Woman Study.

Those achievements show what can be accomplished when leaders and advocates from around the world make a united, concerted effort for change. We know we have much more work to do – but we are confident that by working together, we can make much more happen.

This report provides a brief review of our journey to date.



ELISABETH BAUGH

Chair, World Ovarian Cancer Coalition

WORLD OVARIAN CANCER COALITION BOARD OF DIRECTORS

ELISABETH BAUGH

Chair, World Ovarian Cancer Coalition
CEO, Ovarian Cancer Canada

ANNWEN JONES

Vice-Chair, World Ovarian Cancer Coalition,
Chief Executive of Target Ovarian Cancer, UK,
Co-Chair of the Every Woman Study Expert
Advisory Panel

TAMMY BROWN

Treasurer, World Ovarian Cancer Coalition,
Partner KPMG

ROBIN COHEN

Member of the Board,
World Ovarian Cancer Coalition,
CEO and Co-Founder of the
Sandy Rollman Ovarian Cancer Foundation,
Vice President of the Board of the Ovarian
Cancer Research Fund

JANE HILL

Member of the Board,
World Ovarian Cancer Coalition,
CEO of Ovarian Cancer Australia

EVA SCHUMACHER-WULF

Member of the Board,
World Ovarian Cancer Coalition,
Publisher and chief-editor of the German
ovarian cancer magazine *Mamma Mia!*

WORLD OVARIAN CANCER DAY

Each year on May 8th, women with ovarian cancer, their families and supporters, along with patient advocacy organizations from around the world, come together to raise awareness about ovarian cancer.

World Ovarian Cancer Day started with 23 participating organizations in 2013. It has now grown to encompass activity by nearly 140 patient advocacy organizations worldwide. Since its launch, the campaign has reached over a million people – on World Ovarian Cancer Coalition digital platforms alone.

We have increased followers on the three major World Ovarian Cancer Day social media profiles (Facebook, Twitter and Instagram) by almost 350% and continue to grow and engage new users. Encouragingly, every year, we've seen a rise in people eager to learn more and share knowledge.

The World Ovarian Cancer Coalition Every Woman Study published in 2018 included the shocking finding that two-thirds of women who had been diagnosed with ovarian cancer had either not heard of ovarian cancer or knew nothing about the disease prior to their diagnosis. We now know just how important World Ovarian Cancer Day is.

As we move forward, we are committed to building on the solid foundation for raising awareness we have established with World Ovarian Cancer Day.



THE EVERY WOMAN STUDY

We established the World Ovarian Cancer Coalition because the success of World Ovarian Cancer Day told us we could do much more as a global force for change.

But we also knew that the kind of transformational change we were aiming for needed to be supported by a solid evidence base. In 2017, the Board of the World Ovarian Cancer Coalition took the decision to commit significant resource to undertake a global study to establish this evidence base.

The outcome of that decision is the World Ovarian Cancer Coalition Every Woman Study. This ground-breaking Study encompasses a comprehensive literature review, a survey of over 1,500 women living with a diagnosis of ovarian cancer worldwide, and input from many patient advocacy organizations and clinicians working in this field.

Because of the Every Woman Study, we now have evidence of the shockingly low levels of awareness of ovarian cancer that can result in unnecessary delays in diagnosis. We have evidence of wide variations within and between countries relating to access to specialist treatment, including access to genetic testing and clinical trials – variations that mean that many women may be missing out on treatments that have the potential to improve survival and quality of life. The Study also highlights the significant work that is still to be done to ensure that all women have access to the emotional and practical support and information they need to help them live better with this disease.

But encouragingly, the Every Woman Study also gives us evidence of good practice: good practice that, if shared, could help bring standards up across the board.

It is our view that no single partner, including the Coalition, can address the challenges highlighted in the Every Woman Study. However, the report provides a starting point for us all.

As we move forward, the World Ovarian Cancer Coalition will work hard to engage with the community, including women with ovarian cancer, to map out a course for change that involves us all. For our part, we are already working with partners on the development of a Global Ovarian Cancer Charter.



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KEY WORLD OVARIAN CANCER COALITION MILESTONES

2012

- Global patient advocacy leaders agree to establish a World Day to raise awareness of ovarian cancer.

2013

- World Ovarian Cancer Day was launched on May 8, 2013. Twenty-three patient advocacy organizations participate in the day.

2014

- Global ovarian cancer patient advocacy leaders meet in London, UK and discuss potential for a greater global collaboration.
- World Ovarian Cancer Day campaign utilized a digital pledge to increase awareness.

2015

- A proposal to establish a World Ovarian Cancer Coalition receives unanimous support by ovarian cancer advocacy organizations meeting in Madrid, Spain.
- World Ovarian Cancer Day campaign focuses on the theme “Celebrate the Unbreakable Bond of Women”.

KEY WORLD OVARIAN CANCER COALITION MILESTONES

2016

- The World Ovarian Cancer Coalition is established as a legal entity in March 2016. Three board members are confirmed from Canada, the UK and the US. Over 130 organizations from 34 countries join as partners.
- The World Ovarian Cancer Coalition Board holds its first face-to-face planning meeting in Toronto, Canada.
- The World Ovarian Cancer Coalition appoints a part-time Project Director and Social Media Manager.
- World Ovarian Cancer Day campaign focuses on sharing knowledge with the #KnowNow campaign.

2017

- The World Ovarian Cancer Coalition website is launched. Creative agency Haft2 create a brand that reflects the strong global network and passion.
- The World Ovarian Cancer Coalition Board meet in Toronto and discuss the urgent need for a global ovarian cancer evidence base.
- The Every Woman Study gets underway; Study Director and International Expert Advisory Panel are appointed.
- Three new World Ovarian Cancer Coalition Board members are appointed from the US, Germany and Australia.
- World Ovarian Cancer Day campaign theme focuses on “Your Voice Has Power”.

2018

- Updated global ovarian cancer statistics from the Every Woman Study are released and are widely covered in the media.
- The Every Woman Study Survey is launched in 15 different languages. Over 1,500 women from more than 44 countries respond to the survey.
- One new World Ovarian Cancer Coalition Board member is appointed from Canada.
- The World Ovarian Cancer Every Woman Study is launched in Munich at the European Society of Medical Oncologists. Global media coverage is extensive.
- The World Ovarian Cancer Coalition starts the development of a Global Ovarian Cancer Charter.
- World Ovarian Cancer Day campaign theme celebrates that the voices of women possess many attributes – “Your Voice Has Strength, Passion, Truth, Hope and Power”.

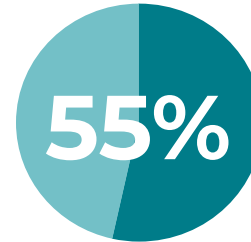
BY THE NUMBERS

OVARIAN CANCER STATISTICS



762,000

estimated number of women around the world living within five years of an ovarian cancer diagnosis

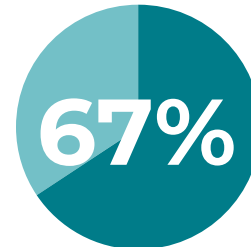


predicted increase by 2035 in the incidence of ovarian cancer worldwide



7th

most common cancer and the **8th** most common cause of death from cancer in women in the world



predicted increase by 2035 in deaths from ovarian cancer worldwide



239,000

estimated cases of ovarian cancer worldwide (2012)

THE WORLD OVARIAN CANCER COALITION EVERY WOMAN STUDY



1,531

The number of women living with an ovarian cancer diagnosis that completed the Every Woman Study survey



44

countries represented in the Every Woman Study Survey



15

The number of languages the Every Woman Study survey was available in



37

clinicians from 15 different countries that contributed to the Study

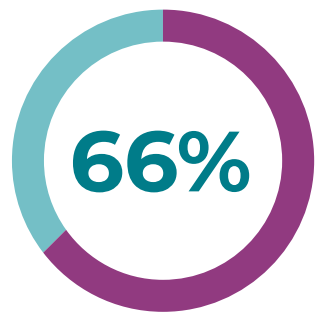


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THE EVERY WOMAN STUDY KEY FINDINGS

SYMPTOMS



of women had not heard of (or heard of but knew nothing about) ovarian cancer prior to diagnosis



of women had experienced multiple symptoms prior to diagnosis

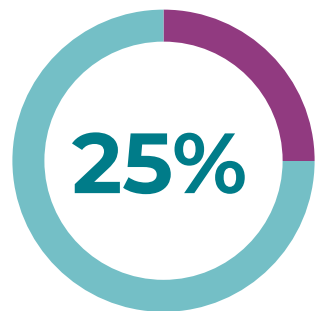


average number of weeks from first symptoms to diagnosis



of women had not had genetic testing prior to diagnosis

CLINICAL TRIALS



of women asked about joining a clinical trial



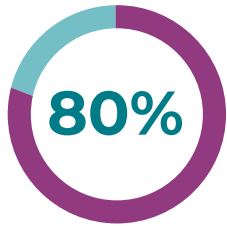
of women interested in taking part in a clinical trial



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GENETIC TESTING

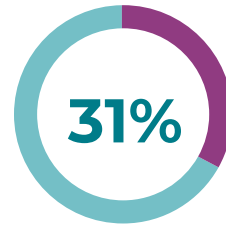


of women with two or more close relatives affected by ovarian cancer prior to their own diagnosis not been tested for faulty genes



variation in genetic testing between 7 countries – Japan, Hungary, Brazil, Italy, Canada, Australia and USA

ACCESS TO TREATMENTS

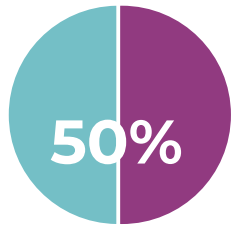


of women whose finances had been affected by a great extent by ovarian cancer diagnosis



variations in estimates from clinicians about percentage of women in their country who access treatment by specialists

INFORMATION

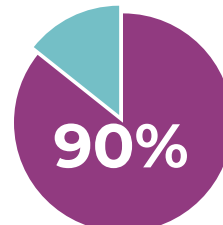


of women get all the information they need at the time of diagnosis



of women were able to find all the information they needed

MIND AND BODY



of women left with long-term side effects from ovarian cancer treatment, including both physical and mental health issues



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6
YEARS OF
THE WOCD
CAMPAIGN



**OVER
1 MILLION
REACHED
SINCE 2013**

SOCIAL MEDIA GROWTH FROM 2013–2018



Social media followers increased by 350% from 2013–2018 (FB, Twitter & Instagram)

140



Number of participating organizations

50



Participating countries

45

The number of languages World Ovarian Cancer Day campaign messages are shared in

Facebook Likes



2013
3,113
2018
13,474

Twitter Followers



2013
330
2018
2,240

Instagram Followers



2013
269
2018
1,013



LOOKING TO THE FUTURE

The World Ovarian Cancer Coalition will continue to highlight and tackle the changes needed to transform survival and quality of life for every woman with ovarian cancer, wherever she may live.

Each year, on May 8th, we will celebrate World Ovarian Cancer Day with our partners and supporters around the world. Year-round, we will share crucial information about ovarian cancer, including information about signs and symptoms to make sure that awareness of ovarian cancer is always in the spotlight.

We will continue to share the findings of the ground-breaking Every Woman Study and engage in important discussions about what we, as a community, need to do. That includes consulting on the development of a World Ovarian Cancer Coalition Global Ovarian Cancer Charter that we will launch in 2019.

We will work hard to build the World Ovarian Cancer Coalition in a way that is diverse and representative of the global ovarian cancer community.

We will also work hard to secure sustainable funding to ensure that we can undertake this important work and support our partner organizations around the world.

LOOKING TO THE FUTURE

JOIN US

Be part of a global movement dedicated to improving survival and quality of life for every woman with ovarian cancer – wherever she may live. Our partner organizations receive World Ovarian Cancer Day campaign materials, including social media posts and regular Coalition Newsletters with updates on our work and how you can contribute to specific Coalition projects.

For more information about joining us, please visit our website at worldovariancancercoalition.org or contact cmackay@worldovariancancercoalition.com.

WORLD OVARIAN CANCER DAY

For more information about World Ovarian Cancer Day, visit ovariancancerday.org.

Follow us on social media



CONTACT DETAILS

World Ovarian Cancer Coalition

Company Name: WORLD OVARIAN CANCER COALITION

Business No. 778772699RC0001

Registered office address:




205 - 145 FRONT STREET EAST

TORONTO, ON M5A 1E3

CANADA

cmackay@worldovariancancercoalition.com

Working to ensure the best possible chance of survival and quality of life for every woman with ovarian cancer, wherever she lives.

 @ovariancancerco
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To join us, visit the website worldovariancancercoalition.org



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