

ACTION

Autumn 2024

OVARIAN CANCER ACTION



**OUR PLEDGE TO WOMEN
WITH OVARIAN CANCER**

CHANGING WOMEN'S LIVES IN 5, 4, 3, 2, 1...

Every day, countless women face the frightening reality of an ovarian cancer diagnosis. The journey from initial symptoms to diagnosis can be long, and the options for treatment can be limited.

We know late diagnosis, limited treatment options, and recurrence are some of the unacceptable reasons women are dying from ovarian cancer.

Despite these challenges, there is hope. Ovarian Cancer Action is dedicated to transforming this reality, making sure that every woman receives a timely diagnosis and the best possible care.

With your help, we've driven some of the biggest ovarian cancer research breakthroughs of the last two decades.

But we need to do more, and we will do more. I'm delighted to share our five key goals that we know will save more lives.



Cary

Cary Wakefield
Chief Executive
Ovarian Cancer Action



1. EFFECTIVE NEW TREATMENTS

“I know only too well that treatment options for ovarian cancer patients are really limited and that needs to change. The knock-on effects of surgery and chemotherapy can be tough and life-long. It took me a good while to recover from my treatment and I can no longer have biological children. With more and better treatment options available, things could have been different.”

— Alex, an ovarian cancer patient

Fortunately, surgery and chemotherapy are no longer the only options for ovarian cancer treatment. We now have some treatments that use drugs to precisely attack cancer cells and stop cancer from growing and spreading.

But for most, these only extend the time before the cancer returns – surgery and chemotherapy are still the most common way to treat ovarian cancer.

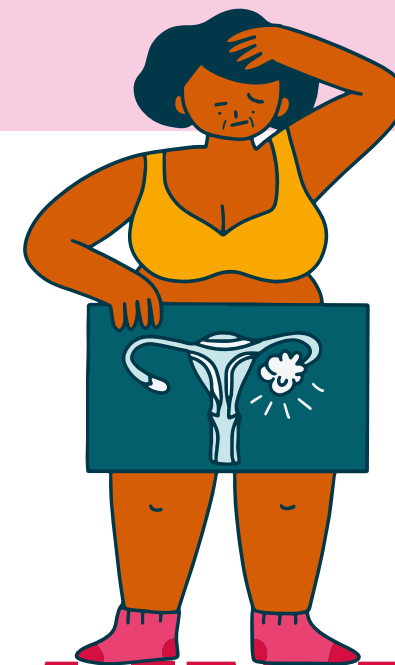
We are committed to investing in new drugs and personalised treatments that will give women longer and save their lives.

2. DETECT CANCER EARLY

The earlier ovarian cancer is detected, the better chance a woman has of survival. But there is no national screening programme for ovarian cancer in the UK. There simply isn't a test that reliably spots ovarian cancer at an early stage.

This needs to change.

Early detection through national screening would save countless lives. That's why we are making it a long-term priority goal.



1 IN 5

Only 1 in 5 gynae cancers has a screening test. Incredibly, cervical screening has halved the number of cases since its introduction. But we can't keep waiting for ours. We need one now.



3. MAKE PREVENTION A POSSIBILITY

“The knowledge of my BRCA2 gene fault is a gift; a gift that could ultimately save my life. Although I may never go on to develop either of these cancers in my lifetime, there's no doubt in my mind that I want to have risk-reducing breast and ovarian surgeries.” – Lyndsey

We are discovering and sharing information on risk, so every woman knows her options and can take control of her future. For instance, there are inherited gene faults (sometimes known as a gene mutation) like BRCA that significantly increase the risk of developing ovarian cancer.

We want to ensure every affected family in the UK has easy access to testing and clear, helpful advice. This information gives entire families the chance to protect their health.

4. MAKE CARE EQUAL

“I’ve sadly realised how disparate the different NHS trusts are, completely segregated and working almost in silos doing their own thing.” – Jo, ovarian cancer patient

No woman should lose her life to ovarian cancer because of her age, her race or where she lives.

We are committed to making sure every woman has the best treatment possible and making quality care equal across the UK.



If you feel just as passionately as we do, donate today at ovarian.org.uk/power-change Together, we can change the future for all women facing ovarian cancer.



5. SHARE THE WARNING SIGNS

In 2009 we led the campaign for the Department of Health to recognise the four main symptoms of ovarian cancer – ending the myth that ovarian cancer is a silent killer.

This was a crucial step forward, but our work doesn’t stop there. We are committed to ensuring that every woman knows the signs to look out for, because we know that early diagnosis is key to saving lives.

95%

If a woman’s cancer is caught in stage 1, she will have a 95% chance of survival, but if she is diagnosed at stage 4, her chance of survival decreases to just 16%.

A LONG-TERM GOAL IS WON DAY BY DAY

Article by Dr Paula Cunnea

In the relentless fight against ovarian cancer, every day presents new challenges and new opportunities for breakthroughs. Dr. Paula Cunnea shows this dedication every day through her groundbreaking research, made possible by your support. Her work is not just about understanding the disease, but about finding ways to outsmart it.

Hello, I’m Dr. Paula Cunnea, and every day I wake up determined to make a difference in the fight against ovarian cancer. This disease is relentless, but so is our team.

In the lab, we face challenges head-on. Our research is not just about data and experiments; it’s about people. Every tumour sample represents a woman’s story and her hope.

After starting my research career at the Karolinska Institute in Sweden, I joined the Ovarian Cancer Action Research Centre in 2012, where I’ve been deeply involved in projects that strive to improve outcomes for women with ovarian cancer. Our team is committed to every part of this fight, from early detection and diagnosis to creating new treatments and tackling chemotherapy resistance.

Personalised treatment should be a necessity, not a luxury

One of our most critical projects I’m working on involves trying to understand the most common type of ovarian cancer (high-grade serous carcinoma or HGSC). HGSC typically responds well to chemotherapy initially, but it almost always recurs, often spreading throughout the abdomen. And when it spreads, it changes too.

This means that when doctors analyse only one tumour sample to help treatment decisions, they are probably missing vital information.

So how do we design better treatments? How do we ensure each woman gets the right therapy for her specific cancer?

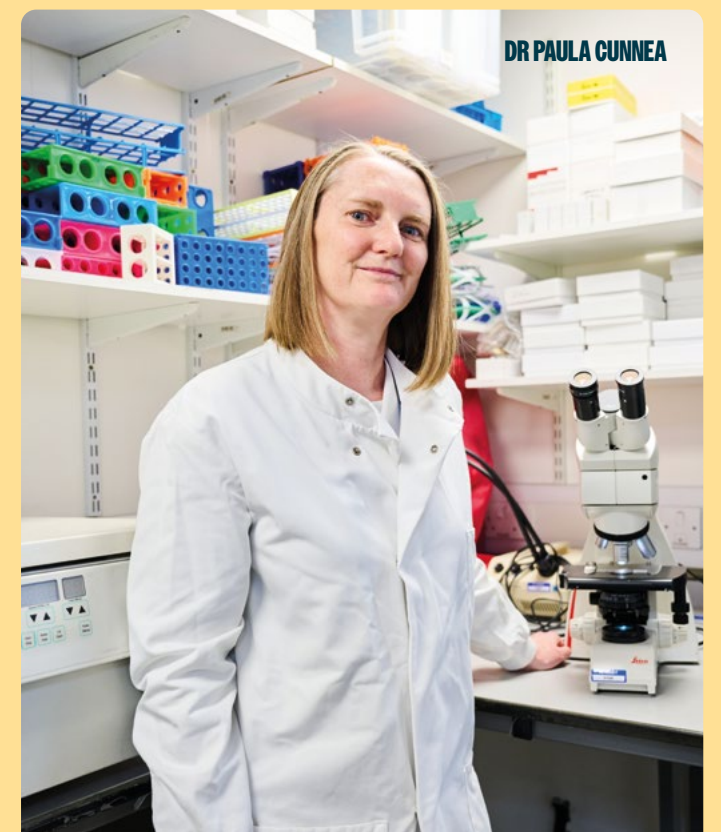
In our initial study of over 40 women, we found that 1 in 5 had variable test results across

multiple tumours, suggesting they might not be receiving the most effective drugs.

Fundamentally, this means that personalised treatment should be a necessity, not a luxury. Each woman’s cancer is unique, and her treatment should reflect that.

We are about 18 months into this five-year project and are currently still collecting and analysing samples. Although we are still in the early stages, the potential impact of our findings could be enormous.

By understanding how tumour samples can vary within a single person’s cancer, we can tailor treatments more accurately, improve survival rates, and enhance the quality of life for many women.





WORKING WITH CORONATION STREET

Article by Marie-Claire, Head of Research at Ovarian Cancer Action

The character of Toyah Battersby on Coronation Street recently faced a shocking diagnosis: ovarian cancer. This storyline was inspired by the real-life experiences of women and crafted with our help to raise awareness about the importance of rapid diagnosis.

When I first started at Ovarian Cancer Action a decade ago, many were still calling ovarian cancer a silent killer. Today, over five million viewers each night are watching a young woman navigate a diagnosis and treatment that affects over 7,500 women every year.

When Coronation Street first approached us with their idea for Toyah Battersby's storyline we had some concerns. There's a lot of misinformation online about using pregnancy tests to diagnose ovarian cancer. We knew that weaving an ovarian cancer storyline into the UK's most watched soap would reach millions, breaking the silence and stigma often associated with this disease. But we were clear that we had to help do it in a way that didn't add to that misinformation.

Right from the start these concerns disappeared. We were so impressed by Coronation Street's commitment to medical accuracy. We worked with the storyline developers right from the beginning, shaping Toyah's diagnosis into a rarer form of the disease – germ cell ovarian cancer – to bring the drama of Toyah's pregnancy storyline together with the very rare instances where a positive pregnancy test can indicate ovarian cancer.

From that moment onwards we provided the storyline team with all sorts of briefings – from what scans she would be having, her treatment

regime, to the conversations she would be having with her doctors. Most importantly we've shared stories from patients who have experienced the same diagnosis as Toyah. Our role was to ensure that the storyline was not only accurate but also reflective of real patient experiences.

Despite it being a hard storyline, it's also been a lot of fun. We've had some light-hearted moments reading through scripts. Toyah hasn't just had to navigate a rare ovarian cancer diagnosis, but also an affair with her sister's husband, while her sister is busy in a cult... The life of a soap character is tough!

Ovarian cancer has been mentioned multiple times in The Sun, Daily Express, OK! and The Metro as well as major regional papers.

Working with the Coronation Street team has reaffirmed how important partnerships are. By combining our expertise in women's health with the show's storytelling prowess, we've managed to touch hearts and minds in a way that few campaigns can.

Together, we have created more than just a storyline; we have sparked conversations, increased awareness, and most importantly, given hope to countless women and their families. This is the true essence of our work, and I am proud to have been a part of it.



THE REAL STORY BEHIND THE SOAP

When Coronation Street came to us with Toyah's storyline, it reminded us of our supporter Sharon's diagnosis journey. Sharon's experience mirrors that of many women who face ovarian cancer, often with little warning and amidst other life responsibilities. Her story highlights the critical need for rapid diagnosis and effective treatment options.

"When I was diagnosed with ovarian cancer at age 40, I couldn't believe it. I'd been both a nurse and midwife, and my Aunt had died of ovarian cancer – but I'd still never considered ovarian cancer an option. I didn't feel ill! I had a bit of bloating and was tired, but I was also a Mum of three young kids, so being tired was pretty normal."

Initially, her doctor thought she was pregnant due to her symptoms. "He did everything bar deliver the baby, he was so sure I was pregnant. I was shocked, and confused – because I knew I wasn't pregnant even though, to be fair, to my GP I did look it. Looking back now, I think he pressed the point so much because he hoped I was pregnant – as anything else would be far scarier."

A negative pregnancy test led to further tests, and a scan revealed the true cause... stage 3 ovarian cancer. "I saw an old colleague as I went for the scan. She tells me now she had the fright of her life seeing me walk in with the mass in my tummy."



There's a huge amount of hope in this research.

Every day is different, filled with unique challenges and opportunities. It's not just the hope that our research will improve the outlook for patients and their families; it's also the daily inspiration from our dedicated team.

Working with brilliant scientists, like Professor Christina Fotopoulou, and seeing the real progress we make together is truly motivating. Whether we are planning experiments, analysing data, or preparing grants for future funding, the goal is always the same: to make a real difference in the fight against ovarian cancer.

Your belief in our work gives us the strength to keep pushing forward. Thank you.

Paula

Dr Paula Cunnea
Researcher
Ovarian Cancer Action Research Centre

I still didn't consider cancer."

Once the diagnosis was confirmed, Sharon thought of the grim statistics and her late aunt. However, her doctor's words, "I don't work in statistics, I work in people," gave her hope. Her treatment started quickly with a total hysterectomy and chemotherapy.

"This time was so tough. My children remember random snippets – the soft toys we gave them each to cuddle and comfort them, the time they spent at their Grandparents during the summer whilst I recovered, the Lucozade next to my bed. Missing time with my children made me so incredibly sad, but it was also the thing that made me fight the hardest to get better."

Sharon's husband played a crucial role in her journey. "My husband was incredible. The cancer diagnosis was a shock to me, and just as much to him. He now had to be Mum and Dad, and he did it whilst keeping so positive. After my fifth round of chemo I asked him if he thought I might die, and he said 'I don't know.' I appreciated the fact he respected me enough to be honest, and loved me enough to know it's what I needed at the time."

Sharon was eventually given the all-clear and has since cherished many significant family moments, including watching her children graduate, attending their weddings, and meeting her first grandchild.

By raising awareness and educating the public, we can change the narrative around ovarian cancer and give hope to those who need it most.

Together, we can make a difference in the lives of women affected by ovarian cancer, just like Sharon.



500

As Toyah's storyline played out throughout August, 'ovarian cancer' was mentioned over 500 times in the media. That's a massive 10 times the usual monthly average – bringing much – needed awareness of this disease.

SHARING REALLY IS CARING

By sharing symptoms, diagnosis, treatment and life after ovarian cancer you can help other women and families in so many ways. Share your story at ovarian.org.uk/share-your-story

GENETIC TESTING

Jo Stanford lost her mother to ovarian cancer in 2006. Here she shares her experience, and the incredible impact genetic testing has had on her family.

Jo, how did ovarian cancer first impact your life?

I never really knew anything about ovarian cancer before 2003. It wasn't on my radar until my mum was diagnosed at the age of 53. Her diagnosis came after multiple visits to her GP with typical symptoms. Despite the challenges, she remained positive.

Were you aware of any family history of cancer?

It was my mum's GP who noticed a pattern. My grandmother had passed away from breast cancer at 41, and my mum's ovarian cancer diagnosis raised red flags. We were referred to a genetic counsellor and discovered a wide history of breast and ovarian cancer in our family tree so my mum decided to have the testing done.

What did the genetic testing reveal?

After my mum passed away in March, we received results showing she had a faulty BRCA1 gene. This explained the prevalence of cancer in our family and meant there was a 50/50 chance that her children inherited the gene fault.

How did you feel about undergoing genetic testing yourself?

I initially went through genetic counselling at age 22 but decided against testing at that time. It wouldn't change anything in my medical care at that age, and I didn't want to base my life decisions on the results.

What led you to finally get tested?

After having our first child, my husband and I were struggling without family support. Knowing I wanted to start risk-reducing surgeries in my early thirties if I had inherited the faulty gene, I decided to get tested so we could make decisions about having more children sooner rather than later. The results showed I did inherit the gene fault, giving me an 87% lifetime risk of breast cancer and up to 60% risk of ovarian cancer.

What steps did you take after learning about your genetic risk?

When I turned 30, I had a risk-reducing double mastectomy with reconstruction. This reduced my breast cancer risk from 87% to under 5%.

What about your ovarian cancer risk?

Unfortunately, there is no reliable screening for ovarian cancer. So, following recommendations I had my ovaries and fallopian tubes removed at 36. The earliest this is recommended varies depending on which gene fault you carry, but for BRCA1 that's 35. This is because the surgery puts you into immediate menopause which carries long-term health risks.

Looking back on your experience Jo, how has your journey with your mum's ovarian cancer and genetic testing shaped your perspective on life and health?

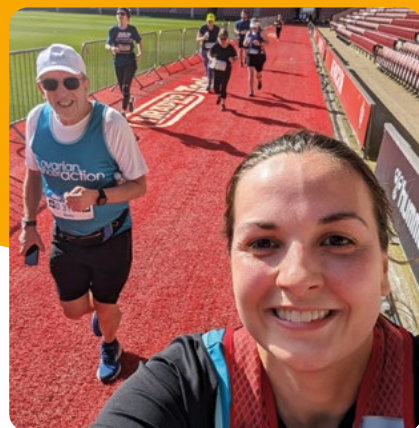
My mum's ovarian cancer and the discovery of the BRCA1 gene fault have made a profound impact on my life. Losing her was incredibly painful, but it also gave me the knowledge and power to take proactive steps to protect my own health and that of my family. I deeply miss my mum and feel her absence in every milestone and daily moment, but I try to keep her memory alive and ensure my children know about the incredible woman she was. Her strength and love continue to inspire me every day, and I'm grateful for the ability to take control of my future, something she didn't have the chance to do.



PEOPLE POWER



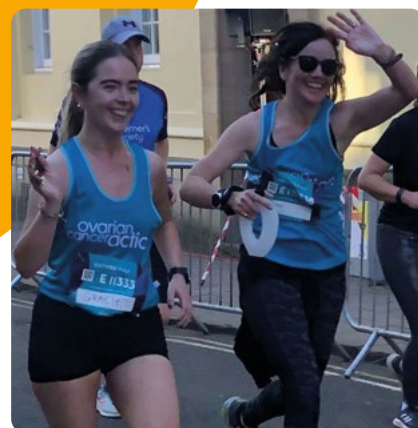
Meet our dedicated runners and walkers who are pounding the pavement, not just for miles but for a purpose – to raise vital funds for Ovarian Cancer Action.



ANDY AND AMY

“We sadly lost our beautiful Nanny Pat to ovarian cancer in 2023. Challenging ourselves to run a half marathon was a special way to remember how brave she was, and we wanted to raise money for Ovarian Cancer Action in the process to help improve earlier diagnosis and treatment for others in the future.”

This dynamic duo took part in the Southampton Half Marathon 2024, raising more than £2,000 in memory of Andy’s Nanny Pat and Amy’s partner’s Aunt Lola. Their dedication is a testament to the power of community and love.



ANNE, GRACE AND HARRY

“Helping to raise much needed funds for continual research into Ovarian Cancer treatments and hopefully a cure; and by trying to raise awareness of the initial symptoms, so that any diagnosis is caught as early as possible. Personally to my family it meant running in memory of my beautiful sister Catherine, who we all miss everyday.”

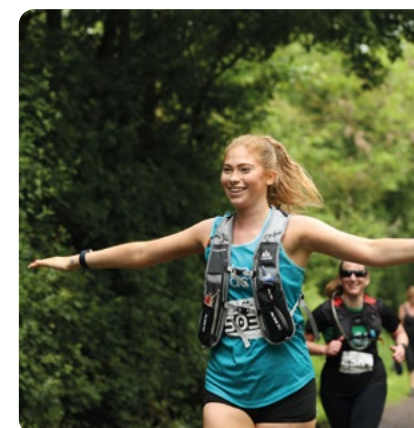
Running the Oxford Half in October 2023, this spirited trio honoured the memory of Anne’s sister, Catherine. Their run was filled with energy and purpose, turning every mile into a tribute to Catherine’s legacy.



LIBBY

“Walking and cycling in aid of Ovarian Cancer Action helps me remember my friend who sadly died of this awful cancer and makes me give thanks for my own health and fitness.”

Libby has taken part in multiple events, raising over £5,000! She recently walked 100km from London to Brighton in just two days. This has all been in memory of her dear friend Elaine who loved a walk and the Seven Sisters.



HOLLY

“By running for Ovarian Cancer Action, I get to honour my nanny’s memory and the incredible woman she was and turn my grief into a force for good by raising money to support vital research to improve treatment.”

Holly took part in the Draycote half marathon in memory of her wonderful nanny, Sandy, who passed away in November last year. Despite facing three complex surgeries, Sandy’s strength and selflessness shone through and left a lasting impact on Holly.

FANTASTIC FLORENCE

Florence has raised an astounding £55,000 so far, by setting up a living tribute with us and raising money year after year. We asked her what motivates her.

“I support Ovarian Cancer Action as they offer hope in the face of despair.

I was diagnosed in 2010 and given a prognosis of 12 to 18 months. It’s a miracle I’m still alive, but I’m alive because incredible scientists have made breakthroughs which have found solutions to this horrid disease.

There are many women who aren’t as lucky as I am. I’ve seen too many of my friends die from this awful disease and more breakthroughs need to be made. But they can only be made through research.

So I fundraise and volunteer for Ovarian Cancer Action, because the more funding we have the more research can take place and the better the outcomes for more women.”



2025 EVENTS

Feel like joining us for an event next year?

Find out how you can get involved at ovarian.org.uk/2025-events

THANK YOU FOR ALL YOU DO

At Ovarian Cancer Action, we're determined to reshape what the future looks like for all women – and your support can help us get there.

We urgently need more treatments, more screening, better prevention and care, and quicker diagnosis. We need it for all the women in our lives.

To donate now, go to
ovarian.org.uk/power-change

OVARIAN CANCER ACTION

f ovariancanceraction @ ovariancanceraction X @OvarianCancerUK info@ovarian.org.uk

🏠 Ovarian Cancer Action, 483 Green Lanes, London, N13 4BS ☎ 020 7380 1730 🌐 www.ovarian.org.uk

Charity registered in England & Wales (No. 1109743) & Scotland (No. SC043478)

