

ovarian.canceraction

My journey

Follow Alexandria's journey from survivor to researcher

The road ahead

Meet Prof. Ahmed and his team leading pioneering research What a walk

Find out about this years amazing achievements





n this deeply personal account, Alexandria shares her journey from surviving ovarian cancer to working at the Ovarian Cancer Action Research Centre. It is a story of resilience and determination. Through her own experience, she talks about the invaluable role that donations play in funding life-saving research.

In the face of adversity, the human spirit has an incredible capacity to rise above challenges, to find strength in the darkest of moments. I want to share my personal journey, from surviving ovarian cancer to becoming a researcher at the Ovarian Cancer Action Research Centre.

When my symptoms started I was approaching my final year of university. I was only 20 years old.

The cramps were unbearable, but the healthcare professionals I spoke to brushed it off. It was frustrating, to say the least. Deep down, I knew this wasn't normal for me, so I persisted, and finally, they discovered a massive cyst on my right ovary.

That's when the reality hit — after the surgery to remove the cyst, I was told I had ovarian cancer.

It was scary, especially when they suggested an emergency hysterectomy. I took a step back, explored my options, and decided to have my right ovary removed for now, with chemotherapy and follow-ups to monitor my progress.

I'm sure, looking back, this shocked the doctors. But in that moment, I was resolute. I wanted to finish my education and put this chapter behind me as quickly as I could.

My journey didn't stop there. Through my own personal battle, I learnt first-hand how the lack of information and guidance affects ovarian cancer patients. I knew we needed change, and we needed it fast. I also know how important it was for me to have been diagnosed early. It probably saved my life.

So, armed with a unique patient perspective and of experience in laboratory research, I eventually embarked on a PhD program focused on ovarian cancer research. I seized the opportunity to join the prestigious Ovarian Cancer Action Research Centre in London, working under the guidance of Professor Iain McNeish.

At the Centre, we're focused on research that can transform the lives of women with ovarian cancer not just prevention and detection, but also treatment.

Personally, I'm working on a device that allows us to test a combination of treatments on tissue samples.

We're hoping to use this research to offer a more personalised treatment for women with ovarian cancer, because we know that every woman is different, and that this type of cancer is extremely complex.

But here's the thing, ovarian cancer research has been historically underfunded, and quality research is urgently needed but it comes at a cost — everything from lab coats to microscopes cost a lot. It's an investment worth making though, because it means we can bring better opportunities to those battling ovarian cancer.

This chronic underfunding is one of the reasons why last March, I signed up to Walk in Her Name, an event organised by Ovarian Cancer Action during Ovarian Cancer Awareness month. I decided to walk 100km in my local area to raise funds and spread awareness about this disease.

I can tell you it was worth every step, every donation, and every ounce of support. Thousands of people like me across the UK walked with a shared purpose, driven by a collective determination to make a positive impact in the fight against ovarian cancer. I am so grateful to everyone who donated to my efforts and believed in the cause.

Alexandria's unwavering determination and commitment to making a difference in the lives of women affected by ovarian cancer is an inspiration to us all. Through her work and the support of people like you, Alexandria strives to accelerate progress in ovarian cancer research, mirroring the successes seen in other cancer types.





Scan this to sign up for next year's event



Join thousand of people who will be taking part in our next Walk In Her Name event, in March 2024.

Sign up today at ovarian.org.uk/walk

# We are unbreakable

In the face of ovarian cancer, the strength of women shines through. These remarkable women have refused to let cancer define them and through their stories, we witness first-hand the critical role that research plays in providing hope for the future.

"I was diagnosed at just 20. In January 2023, I will be two years free of ovarian cancer. I look back at photos and I don't even recognise myself anymore.I still have down days where I think about it a lot, but it's changed me for the better.'



In November 2022, I reached the magic five years since my original diagnosis. I've been on olaparib since June 2021. It's always there, in the back of your mind. But as time goes on you worry a little less each day. My partner, family and friends have been incredible throughout my journey.



"This photo still stops my heart. I remember how scared I was, only 40 when diagnosed, and how I was trying to put on a brave smile. I've just celebrated 10 years since my diagnosis, and I feel so lucky to be here. I want other women to have the best care and treatment, that's why I support Ovarian Cancer Action."



Natalie, 40

I still feel like one of the lucky ones that I was tested and treated early enough that the cancer was contained.

My scar is now just a part of me! I was always pretty body shy - but knowing what my body can take and what it's been and still going through - I know I am tougher than I ever thought possible.





"This is one of the first photos I had taken of my scar once it had healed. After my two surgeries, it took over six weeks before I could bring myself to even look at my stomach. I was terrified of what was happening and I suppose this was a very visual and permanent reminder. I thankfully managed to learn to love the scar. It's a daily reminder of what my body went through and how eternally grateful I am to still be here."

"In May 2016 I sat by my 94 year old Grandma's side whilst she died of ovarian cancer. Just over a year later I would be diagnosed myself. I was told I had very little chance of living longer than 5 years and my only option was chemo, it was too dangerous to operate on me. I had a 14-year-old daughter who I wanted to see grow up. In September this year, I made it past the 5 years. Blood tests show my CA125 is rising again, but I'm determined to never give up."



Sarah 40



"This is my visible scar of ovarian cancer for all those who ask me why I don't have children. I was diagnosed when I was 29 years old back in 1997. Even though I have no children I count my blessings every day as I am one of the lucky ones but only because they caught it early."



by Professor Ahmed, whose research is funded by Ovarian Cancer Action

ithout a doubt, ovarian cancer stands as one of the most devastating diseases we face today. Late diagnosis is a formidable challenge, one that my research group is firmly determined to confront.

In research, the fruits of our labour do not manifest instantly; they emerge after countless hours of commitment. However, when a breakthrough occurs, the sense of accomplishment is profound.

One such moment that I can think of, is the discovery of the prevalence of the SOX2 protein in the fallopian tubes of ovarian cancer patients and those at high risk. This finding holds immense potential, offering a path towards the development of screening tests that can detect ovarian cancer at its earliest, most treatable stage.

The journey to improve the lives of women battling ovarian cancer continues. I vividly recall a young patient, merely 22 years old, who faced an exceedingly rare form of ovarian cancer resistant to chemotherapy. Her unwavering zest for life and enduring hope remain a constant source of inspiration.

And because of her determination, I am driven to tirelessly seek new avenues to combat this disease.

#### Advancing towards a new screening tool

The question of a screening tool looms large. Early detection is paramount in enhancing ovarian cancer survival rates. In cervical cancer, we deeply understand the origin and progression of pre-cancerous cells, leading to effective screening through the cervical smear test. Unlocking a similar understanding of ovarian cancer represents a crucial step towards developing a screening tool for early detection.

That is why today, my team is tirelessly working to unravel the early stages of ovarian cancer development and pioneer the world's first screening tool for this disease. And the discovery of the SOX2 protein prevalence in fallopian tubes, which I mentioned before, has already provided invaluable insights.

#### Where we are today

Using cutting-edge technology, we are delving into the intricacies of various cell types within the fallopian tubes to

comprehend how and why they become cancerous. Already, we have identified two key molecules that contribute to the initiation of ovarian cancer.

Furthermore, our analysis of the DNA from over 300 non-cancerous fallopian tubes compared to cancerous ones, suggests that genetic markers alone are insufficient to cause the transformation of healthy cells into cancerous ones.

This discovery brings us closer to constructing a comprehensive narrative of the journey from healthy cells to cancer cells in ovarian cancer. By identifying critical molecules involved in this early transformation, we can uncover new markers that have the potential to revolutionise pre-cancer detection.

#### Hope for the future

Our research journey continues, and I know we can't undertake this endeavour alone. So I would like to thank everyone who has supported Ovarian Cancer Action because it's thanks to you that we can bring hope to future generations of women.

By unravelling the complexities of ovarian cancer, Professor Ahmed and his team aims to revolutionise pre-cancer detection and bring hope to future generations of women.



## Until every woman survives, we won't give up.

At the Ovarian Cancer Action Research Centre, our dedicated scientists are tirelessly working towards ground-breaking advancements in the treatment and care of ovarian cancer patients. But they can't do it alone.

You can help fund vital research and accelerating progress in the fight against this devastating disease. Together, we can see a future where every woman can conquer ovarian cancer.

Will you join us today? Please visit <u>ovarian.org.uk/together</u> to donate online or call 020 7380 1730. Thank you.



Scan this to donate instantly



Your bite-sized round up of the latest news from the lab and beyond!

## Beth Mead: A football star turned OCA champion

Lioness Beth Mead is honoured to be named 'Captain' for the highly anticipated 2024 Walk in Her Name event. With her unwavering dedication during last years walk, Beth will once again spearhead this campaign to raise money and spread awareness for ovarian cancer research. This annual walk brings together people from all backgrounds to partake in a 100km challenge, united in their determination to overcome ovarian cancer. With Beth leading the charge, next year's event is set to raise even more for life-saving research.

Sign up at: ovarian.org.uk/walk



Beth and her mum June, who passed away in January.

## A new drug combo shows positive results

A recent clinical trial has made a significant breakthrough in the treatment of low-grade serous ovarian cancer. The trial tested a new drug combination, avutometinib with defactinib, on 29 patients. The trial showed that the combination treatment was highly effective, with nearly half of the patients experiencing significant tumour shrinkage. This result is almost twice as effective as the next best treatment option, trametinib.

Read more at: ovarian.org.uk/combo-results

## A recipe for improving healthcare

We know too many women are facing unfairness in accessing high-quality care, which reflects on their chances of survival. That's why two years ago, we launched IMPROVE UK, the first major project to tackle the unacceptable inequalities in healthcare for ovarian cancer patients.

The first results have now emerged, identifying the need for prehabilitation. In other words, preparing mentally and physically before starting treatment gives women the best chance of surviving the disease.

Read more about this and other findings at: **ovarian.org.uk/recipe** 



### My body is a temple

Complementary therapies aim to support your physical and emotional wellbeing during treatment. Meditation and mindfulness techniques can provide a sense of calm and inner peace, while acupuncture may help alleviate treatment side effects such as nausea and fatigue. Exercise, nutrition and dietary modifications can also contribute to overall health and vitality. But with complimentary therapies, each individual's journey is unique.

Read more about complementary therapies that can go alongside your usual treatment here:.

Share your experience today: ovarian.org.uk/therapies

#### Research on the run

Dr Katie Baxter and Professor Richard Edmonson, two passionate researchers tackling the postcode lottery through the IMPROVE UK project, participated participated in the Manchester Half marathon to raise funds for Ovarian Cancer Action. A big thank you to Richard and the entire team for their incredible support and congratulations on a job well done!

Feeling inspired? Find a fundraising event near you at: **ovarian.org.uk/ challenge** 



## We've campaigned... and won!

The National Institute for Health and Care Excellence (NICE) has decided to extend access to the game-changing drug olaparib (or Lynparza) to all patients with a BRCA gene mutation. This is a drug that can slow down the progression of the disease. Previously it could only be accessed by patients who had experienced a second relapse - forcing others to endure the agonising wait for ovarian cancer to strike again. It's a big win for ovarian cancer patients, and it's thanks to the ongoing support of donors across the UK.

Read more: ovarian.org.uk/olaparib-news



Are you seeking relief and resilience in your ovarian cancer journey?

Fiona's gentle Yoga sequence could help unlock your inner strength and enhance your well-beings. Watch Fiona's video at: ovarian.org.uk/yoga

### When one is not enough

Our researchers made a revolutionary discovery: relying on a single biopsy from a single location may not lead to the most effective treatment, which unfortunately is the current standard practice. But this is our opportunity to change the game! Due to the complex nature of ovarian cancer, we now know that taking multiple tumor samples from different abdominal sites is vital; so our researchers can now propel these findings forward, driving big changes in the near future!

Read more at: ovarian.org.uk/biopsy-news



## We will not give up until every woman survives ovarian cancer.

We are the scientists, the women diagnosed, their friends and their families. We have one mission – to ensure that every woman survives.

Together, we will fundraise. We will walk. We will fund more life-saving research. We will spread awareness until we break through. Until every woman survives.

### Thank you for joining us.



"This is a type of cancer that people don't talk about much. The truth needs to be shared. I thought a smear test would detect it. We need more awareness and research right away."

Jenna

