

Action magazine



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ovarian. cancer**action**

We've made this magazine with you in mind so tell us what you think! We would love to hear from you.

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We are proud to be a member of the Fundraising Regulator. We promise that our fundraising is respectful, open and honest.

We won't stop now

With your help we're determined to get our research back on track for the women who need it most.

You may have noticed this edition of Action magazine is smaller than usual. With our income hugely affected by COVID-19, we're reducing costs where we can to continue our life-saving work. But now more than ever, we think it's important to keep you updated.

Your continued support has meant we've been able to care for our community throughout lockdown. Our Staying Connected programme for patients is a joint venture with our friends at Ovacome that you can read more about on page 4. You will also find out how we've been doing our bit to ensure those experiencing symptoms visit their GP.

Patients have been our priority and this won't change. But it's now time to get our scientists back in the lab as we've had to put some potentially life-saving projects on hold. Charities like us play a vital role when it comes to funding medical research. We fund innovative projects, allowing researchers to test out promising ideas and start collecting the results they need to attract bigger



funding from Government or industry bodies. Without our initial investment, we risk losing momentum in improving ovarian cancer treatments and, in turn, survival. You can find out more on page 6.

Like most charities, we've been hit hard by the Coronavirus pandemic. We're facing a 50% decline in income this year alone, which will have a direct effect on the amount of research we are able to fund and therefore the number of women we can help. With your help we can make up for lost time.

We know Coronavirus may have made things tough for you too, but if you are able to donate, you can find our donation form at the back of the magazine or you can visit ovarian.org.uk/donate. Thank you for making our work possible.



News in brief

Find out how the pandemic has affected our community and how we have responded.



Staying Connected

We teamed up with our friends at Ovacome to deliver our Staying Connected programme, designed to help you feel connected, supported and informed. Together we've talked, stretched, crafted, laughed, cried and danced our way through

the last five months via
Zoom. We continue to
send weekly emails
with Government
updates and what
they mean for
you or a loved
one, as well
as interesting
things to watch,
do or listen to.
Visit ovarian.org.uk/
stayingconnected for

In March 2020 the country went into lockdown, to stop the spread of coronovirus.

Thousands of you were asked to immediately shield at home, and our researchers were told to leave their labs. All clinical trials were stopped and every fundraising event we had planned was cancelled.

The first thing we did was ask you what you needed. In our online survey, you

told us how we could help you navigate the coming weeks of self-isolation. You said that you wanted the latest information for ovarian cancer patients and to know what it means for you or a loved one. You also said you would like extra support and advice on how to keep your mind busy throughout these uncertain times.

Another concern for us was the worrying news that cancer referrals had dropped

by 75% due to coronavirus. It quickly became apparent that people did not feel safe visiting their GP, but the consequences of staying away could be far greater.

our latest webinars.

In response to all of this we developed two programmes: Staying Connected for patients and Staying Aware, to raise awareness of symptoms and the importance of visiting your GP. You can find out more about both on these pages.

Staying Aware

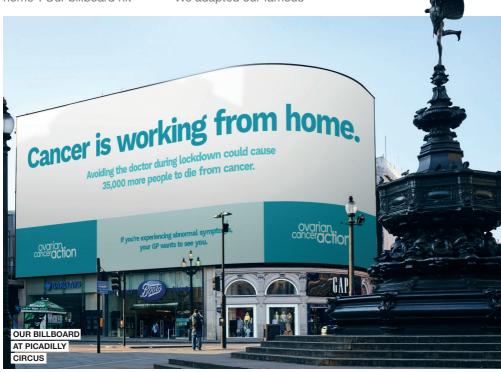
By May, we had learned that cancer referrals had dropped by 75%. Confusing communications from the Government meant people were actively encouraged to not burden the NHS. But cancer doesn't stop because of coronovirus. Coupled with the fact that only 10% of women know the symptoms of ovarian cancer, we knew had to take action.

We took over Europe's biggest billboard in Piccadilly Circus with the message "Cancer is working from home". Our billboard hit

the headlines and sparked conversations across the internet. The message from our CEO was received loud and clear, "If you are experiencing unusual symptoms, your GP wants to see you. And let us be clear, you are not a burden. Catching cancer early actually helps the NHS and even more importantly, an early cancer diagnosis can save your life."

You have also played a huge part in raising symptom awareness during lockdown. We adapted our famous

World Ovarian Cancer Day campaign, so instead of handing out white roses around the country as we have done together in previous years, we grew an online digital rose garden. For the whole month of May we asked you to create your own rose, upload it to our garden, and share it on vour social media with information about symptoms. The campaign was a huge success and you can find out more on on page 8.



How we fund research

Our careful review process ensures that your donations will lead to discoveries.



Thanks to you, we can invest in research projects across three vital areas: prevention, earlier diagnosis and more effective treatments. Improvements in each of these areas will transform the lives of women today and for generations to come.

We do not receive any Government funding, which means our work is exclusively funded by you.

We make funding decisions that follow our guiding principles of being translational, innovative and evidenced-based. Together, we've funded £12.3 million of medical research to date.

OUR HHMT FORUM

Every four years we host our HHMT International Forum

on Ovarian Cancer, which you may have read about in our last edition of Action magazine. The forum brings together the world's leading ovarian cancer experts to discuss and pinpoint what our global research priorities are to help women diagnosed with ovarian cancer.

THE REVIEW PROCESS

When we receive applications, the OCA research team begins a review process to determine if it is worthy of your donations. We are proud members of the Association of Medical Research Charities (AMRC) who set out charity research funding processes. This means that we have strict guidelines to follow and are regularly audited to ensure we are

OUR GUIDING PRINCIPLES

Translational

The research will translate from the lab into real life, and make a difference to women with ovarian cancer

Innovative

We find and fund the people who are asking the key questions whose answers will improve survival

Informed, evidence-based and current

We keep pace with the latest thinking in ovarian cancer research and treatment, guided by our HHMT International Forum on Ovarian Cancer

THE REVIEW PROCESS

HHMT

Sets global research priorities

OCA research team Invites applications for projects

Peer review

Industry experts review the project

Lav review

Input from patients and people affected by ovarian cancer

Scientific Advisory Board

Collates reviews and makes expert recommendations

OCA Board Signs off on final decision

We grant funding and begin lifesaving work

making informed decisions and funding research of the highest standard.

PEER REVIEW

First, a project is sent to be reviewed by expert scientists from anywhere in the world who have a similar research area. A lot of care goes into picking three peer reviewers who will give good insight into the quality of the project, highlighting any strengths and weaknesses that OCA and the Scientific Advisory Board should be aware of.

LAY REVIEW

Next, we'll ask the Ovarian Cancer Action Research Network to review the projects. The network is a nationwide, virtual group of people affected by ovarian cancer who use their experience to help shape our research. It is vital that patients are involved in every project, to help scientists

SCIENTIFIC ADVISORY BOARD

achieve their best work.

The comments from the peer and lay reviewers are then taken to the Scientific Advisory Board (SAB), who makes the final funding decisions. Our SAB is made up of international cancer experts, mainly researchers

and clinicians, covering a wide breadth of ovarian cancer expertise. When reviewing a project, the SAB will consider: How will this research improve the lives of women with ovarian cancer? Is this research already being carried out elsewhere? Does the project represent good value for money? Could findings from this research translate into clinical trials, clinical practice, the pharmaceutical industry or lead to policy change? And much more.

Want to join our OCA Research Network?

Visit ovarian.org.uk/ research-network OCA BOARD Finally, once

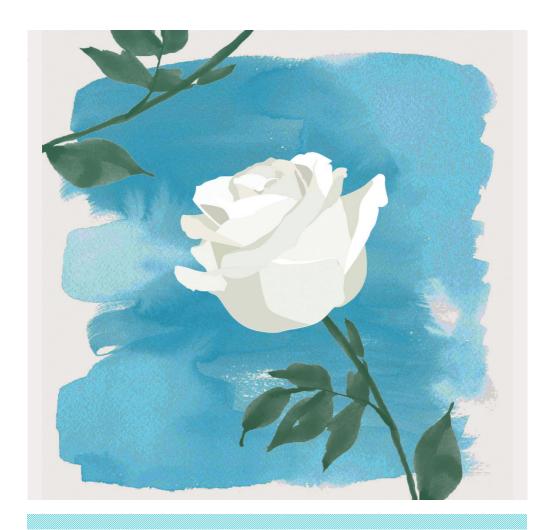
a research
project has been
through all of
these processes
and the OCA Board
of Trustees is satisfied

with the results, we can begin to fund it.

Thank you for sharing our ambition that will make ovarian cancer a survivable disease.

Thanks to COVID-19, our research is at risk. Find out about our upcoming fundraising challenges on page 15 to help us continue funding research that will improve the lives of women with ovarian cancer.

Alternatively, you can visit ovarian.org.uk/donate or find a donate form at the back of the magazine.w



World Ovarian Cancer Day 2020

Friday 8th May was World Ovarian Cancer Day. A day where we raise awareness of ovarian cancer and its symptoms by sharing a symbol of hope: a white rose.

In previous years, with your help, we have handed out thousands of white roses with symptoms cards attached in cities across the UK. Lockdown meant we couldn't take to the streets this year but we refused to let that stop us!

Throughout May, we asked you to help us raise awareness of ovarian cancer and its symptoms by doing these three things:

- 1. Craft your own white rose by painting, baking, knitting, folding or anything else that inspires you.
- 2. Share your rose on social media with symptoms information.
- 3. Upload your rose to our gallery to help us create the UK's largest rose garden.

Together, we planted over 200 roses in our digital rose garden, each with its own message of hope. Our roses were shared far and wide, across your social media channels and by word of mouth. Thanks to you we were able to reach thousands of people with the symptoms of ovarian cancer. From patients to scientists, the whole community came together to raise awareness.

Dr Sarah Spear from the Ovarian Cancer Action Research Centre took part as she is passionate about early detection. She says, "We know the earlier ovarian cancer is detected the better, and that's why it's so important that all women are aware of the symptoms. Whilst our research at the Ovarian Cancer Action Research Centre aims to improve treatment options for women with ovarian cancer, it still all starts with women knowing what to look for and when to go to the GP.

"I made a white rose in May to support Ovarian Cancer Action and help raise awareness. It's a beautiful idea to spread the word and I hope we reach many women



with these lovely roses."

Symptoms awareness and early diagnosis is as important now as it's ever been. On top of the 90% of women

who don't know the symptoms

of ovarian cancer, we have seen a sharp decline in the number of people going to the GP with cancer symptoms due to COVID-19.

But cancer doesn't stop just because we're in a coronavirus pandemic. Early diagnosis is vital. We have been

working in partnership with the NHS to encourage women to visit their GP if they are experiencing symptoms. The NHS is, and always will be, open.

INVOLVED ocarosegarden

GET

Visit ocarosegarden.org.

uk to see all the beautiful roses created throughout the campaign and read the dedications

STAY IN TOUCH

Want to hear about our upcoming campaigns before they happen? Make sure you're opted in to our e-newsletter. We send roughly one to three emails a month and won't share your details with anyone else. Sign up here:

ovarian.org.uk/stayintouch

Another lifetime

Caroline Brown was diagnosed with ovarian cancer in 1994. Now, 26 years later, she reflects on her 'lucky' journey.

It was March 1994 and I had not long celebrated my 37th birthday. I'd been married for 18 years and my daughter Natasha was eight years old. I had felt quite healthy but towards the end of the month I began to get an uncomfortable feeling in my bottom. After a few visits to my GP that didn't help me at all, I asked him to refer me to a bowel specialist. As my husband had health insurance it was only a week before I was able to see one. The consultant examined me and found nothing untoward, but as a final thought asked if he could do a pelvic exam. He found I had a cyst on one of my ovaries and referred me to a gynaecologist.

The next week I had a scan that showed cysts on both ovaries and was booked in to have them removed. I'd had this done twice previously for ovarian cysts so thought nothing of it. The consultant had to ring my husband mid-way through my operation as it became apparent to him that it was cancer he was dealing with. Permission was given for the consultant to go ahead and give me a full hysterectomy. When I came round from surgery it was explained to me what had

happened and that it was good news the cancer had been removed.

I had woke up into a complete nightmare and didn't think I would survive. I was plunged into the menopause and the symptoms were hideous. As if this wasn't enough, I developed the worst anxiety, not that I knew that's what it was at the time. I put everything down to the cancer, of which everyone kept telling me how lucky I was as it had been taken out. Oh yes I did feel lucky! But I actually didn't know what to think.

AN ACT OF KINDNESS

The evenings in the hospital were the worst. I couldn't cope with falling asleep alone. I was very lucky to have my sister Pat who came into the hospital every night and sat with me until I fell asleep. An act of love and kindness that will never be forgotten.

Then it was home to recover and start the chemotherapy. It was an awful time. I thought it was pointless - if I was going to die why put myself through all of that? But I would look at my daughter and I knew I had to do it for her. I wanted to see her grow up at least. She and my husband were my reason to fight back. All the family rallied round to help me through those next six months. My sister-in-law Barbara was very good, looking after Natasha when I was going for my chemo and giving me such mental support when I felt like giving in. Eventually I completed my chemo sessions, not without hiccups along the way, but it was done and all signs of cancer had gone.

"The thing with overcoming cancer is you never really heal your mind, your body gets all the attention"



FEELING LUCKY

I was lucky because my cancer was found early. If I'd been put on a waiting list to see the various doctors I had before the cancer was found, sadly the outcome may not have been as positive as it is today. My consultant told me my cancer was so aggressive, by the time I had finally seen a specialist it would have been so much further advanced. This is why awareness of changes in your body need to be checked out as soon as you can. My symptoms were unusual, so research into early detection is paramount.

This year marks 26 years since my cancer

was found. That's another lifetime I have been able to live and watch my daughter grow up and get married and to be there and watch the births of my two beautiful granddaughters. I do truly feel blessed. My daughter is 35 now, just two years off the age I was when I was diagnosed. I don't want her to ever go through the same!"

TAKE ACTION

Would you like to share your story and help raise awareness?
Email Tori@ovarian.org.uk

Here's to you

Not even lockdown could stop you from fundraising! Thank you for finding ways to keep helping women with ovarian cancer.





PEDAL POWER

Primary school teacher Amy Baker inherited her love of cycling from her grandparents. She took part in Women V Cancer's Ride The Night in memory of her nan, and then continued her training throughout lockdown for the Ride London 100, which has sadly since been cancelled.

She savs. "A huge part of my motivation is raising awareness for others. When my friend lost her mum to ovarian cancer 20 years ago, not much was known about it. When I lost my nan. quite a few years later, little more was known. For a long while, her symptoms were attributed to IBS, and it was too late by the time ovarian cancer had been diagnosed. I want women to know the symptoms, to be able to go to their GPs and tell them they want to be tested. It was too late for my nan, but it does not have to be too late for others."



NORTHERN SOUL

Darren Adnett is running ten 10km races in memory of his friend Debbie Gold, who died of ovarian cancer last year. With races cancelled due to COVID-19, Darren has been honouring the race dates and taking on 10km runs around his local area in Greater Manchester.

He says, "I know Ovarian Cancer Action is helping to find ways to reduce the impact of ovarian cancer, and to improve the lives of women who are diagnosed with the disease. I just want to do anything I can do to help."

THE OCA STEP CHALLENGE

We asked you to complete 295,000 steps during the month of May, one for every woman diagnosed with ovarian cancer globally each year. Throughout May you have walked, run, danced and jumped your steps, raising a total of £30,000!

Feeling inspired? It's not too late to take on your own Step Challenge. Visit stepchallenge.org.uk to get started today.

THE EMLY'S

Various members of the Emly family were set to take part in our London Walk in Her Name but COVID-19 had other plans. With the event cancelled, Maria took on her own Step Challenge and raised £1,200 in memory of her daughter Sarah.

Maria says: "I completed a 6km walk in my garden on my birthday, 4th May, instead. I had a lot of support from family and friends so could not let

them down. The weather was pleasantly warm and sunny with John, who claims to be my trainer, provided encouragement and an espresso at the half-way mark.

"As a family, we have so many happy memories of our life with Sarah, and our lives will never be the same now she has gone.

She always saw the

best in people,
had a great
zest for life,
a delightful
sense of
humour, and
an everpresent smile."

TAKE ACTION

Now more than ever, we need your support to help women with ovarian cancer.

Host a virtual quiz, donate the cost of your commute or take part in a virtual race - there are lots of ways you can help fund vital research.

To become a fundraising superstar, order your free fundraising pack by emailing fundraising@ ovarian.org.uk

Or visit ovarian.org.uk/getinvolved

TEAM ANITA

Andy Leslau and his brothers took part in our Step Challenge in memory of their mum Anita Leslau, raising more than £3,000. He says, "Mum shares her birthday, May 8th, with World Ovarian Cancer Day. She was an avid supporter of Ovarian Cancer Action, so when the Step Challenge was announced, my brothers and I knew what we had to do.

"Ever since her diagnosis in 2009, she was determined to raise awareness of the disease. She always hoped for a future where early



diagnosis can take place for women and a drug to cure this dreadful disease could be found. Every year, 295,000 women are diagnosed with ovarian cancer globally. We walked 295,000 to raise funds that will help these women, and the next generation, survive."

Five minutes with...

Emma Scott, CEO of Beano Studios and OCA trustee

How did you come to be an OCA trustee?

I met the fantastic Allyson Kaye, OCA's President, when I was the CEO of Freesat. My mother died from ovarian cancer and I felt I could lend my strategic and media skills to the Board. Eight years on I've learned a huge amount and I'm immensely proud to be a trustee.

Who was your biggest role model growing up?

I was hugely inspired by Nelson Mandela, his wisdom, sacrifice and his autobiography *Long Walk* to *Freedom* touched so many and started a global dialogue, which is still much needed today.



SNAP POLL

Guilty pleasure:

I love going to the cinema. The art and craft of watching great stories unfolding on the big screen is a joy for me. **Book:** The Amazing Adventures of Kavalier

Chabon Shop: Zara

Film: Mary Poppins

and Clay by Michael

Vietnamese Relax and unwind:

Food:

Currently it's been sitting in my garden, which I feel incredibly grateful

to have.

What do you consider to be your greatest success?

I have been lucky enough to be a mother, although I'm not sure my teenage kids would say I'm a 'success'! From a career point of view, I loved working at the BBC and more recently transforming the Beano comic into a global entertainment business has been guite a blast.

And greatest failure?

Anything sporting! I've had many work failures, but they are all there to learn from.

If you could share one piece of advice, what would it be?

Bring your true self to all you do. Once you do, life starts to get that bit easier.

What keeps you motivated when times are tough?

Family, friends and relentless optimism.

The best thing you've learned during lockdown?

That my kids are turning into really great young people and I have the most

amazing friends. Lots of relationships have strengthened during these peculiar times. It has been very hard for everyone, particularly those who are shielding

 but there have been many unifying moments.

Dates for your diary

Women V Cancer's 100K Your Way

24 July – 2 August 2020 Introducing our first Women V Cancer virtual event. Complete 100km in 10 days and raise funds for women facing breast, cervical and ovarian cancers across the UK. Ride. Run. Walk. The choice is yours.

The OCA Research Relay

1-31 August 2020
Can you walk, run or cycle 500 miles this August to keep our research moving forward? As a team or individual, take on the combined distance between our labs, or a distance of your choice and raise £1 for each mile you complete.



Ovarian Cancer Awareness Month

1-31 March 2021

Join us to raise awareness of ovarian cancer and its symptoms.

Royal Parks Half Marathon 11 April 2021

Usually hosted in October, the half marathon has a new date for 2021. Starting and finishing in London's Hyde Park, you will join 16,000 runners to take part in the 13.1 mile route through central London, taking in the spectacular sites of the capital and the beautiful Royal Parks.

World Ovarian Cancer Day 8 May 2021

Make sure you take part in our white rose campaign.

Women V Cancer's Ride the Night

29 May 2021
Our iconic women's cycle challenge (having been cancelled in 2020) will be back, bigger and better in 2021. Join thousands of women to cycle 100km through central London at night for women with breast, cervical and ovarian cancers.

To find out more visit: ovarian.org.uk/challenges



8-12 Camden High Street, London NW1 0JH Charity registered in England & Wales (No. 1109743) & Scotland (No. SC043478). Inclusion in the Ovarian Cancer Action newsletter does not imply endorsement of a participating organisation or its products.



Take on the most scenic half marathon in London.
Join 16,000 runners to take part in the 13.1 mile
route on closed roads through central London,
taking in the spectacular sites of the capital and
the beautiful Royal Parks.

Register today

Secure your place for £15 with a fundraising target of £500.

Visit ovarian.org.uk/royalparks or call 020 7380 1730 or contact us on fundraising@ovarian.org.uk