ovacome..
ovarian cancer

WINTER ● 2024 ●

RAISING FUNDS AND CHASING THE SUN

THE MAGNIFICENT SIX RIDE 180 MILES FOR A DEAR FRIEND

SAY HELLO TO OUR NEWEST PATRON

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Supportive caring community

Freephone support line:

0800 008 7054

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As I write this column, we're on a high from the annual Touch of Teal event which has raised £350,000 for Ovacome over the past 15 years. The buzz and joy it brings just never seems to wane. Thank you to everyone who made it such a special day. The extra touch of sparkle this year was the announcement of Lady Sewell MBE as Ovacome's newest patron. Adele – you've been an inspiration to so many and we cannot wait to start working with you in your new role.

Summertime is always filled to the brim with events at Ovacome, and you can read about these in more detail on **pages 9 and 13** of this magazine. And don't forget to have a look at **page 8**, where we share some fantastic patient voice research success for those diagnosed with granulosa cell tumour.

Summer is also the time of the year when we look at our planning for our next financial year, which begins in October. As ever, we're led by you, our membership, and the feedback you provided via our consultation earlier this year has proved once again invaluable to understanding what you need from this community. **We're always open to ideas, so if you've got something to say or suggest then email us at ovacome@ovacome.org.uk, I'm all ears!**

And finally, this magazine has got some fantastic opportunities with which to get involved with. Whether it's doubling your donation to us via The Big Give or planning a fundraising event for OCAM **(page 7)**, we couldn't be here without your support. **Contact our fundraising team on fundraising@ovacome.org.uk, they'll support you every step of the way.**

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Thanks to Beat:Cancer for funding our support line.

If there are any topics that you would like us to cover in the magazine, please contact media@ovacome.org.uk

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LADY SEWELL MBE BECOMES OVACOME'S NEWEST PATRON

We are absolutely delighted that **Lady Sewell MBE** has accepted an invitation to become Ovacome's newest patron.

Known throughout the ovarian cancer community for her commitment to raising awareness of the disease, fundraising for ovarian cancer charities and bringing people with an ovarian cancer diagnosis together, Adele was awarded an MBE in the 2023 New Year's Honours list for her charitable services to ovarian cancer.

Following a diagnosis of breast cancer at 35 years old in 1999, Adele noticed what she would later understand to be the early signs of ovarian cancer six years later in 2005, but it wasn't until September 2007 that ovarian cancer was diagnosed. Adele carries the BRCA2 gene change, along with three of her four siblings.

Victoria Clare, Ovacome CEO said "We've known Adele since 2008 and she has been tireless in her quest to support others in the ovarian cancer community, powerfully using her voice to share her own experiences and advocate for others.

"It felt appropriate to announce Adele's patronage at the Touch of Teal event on 7 September 2024, which, led by Adele, has raised more than £350,000 for Ovacome in the last 15 years."

"As a membership organisation, we are led by members of the community, and we know this partnership with Adele will only strengthen what we are able to achieve. We can't wait to get started."

Adele said, "Ovacome has helped me in many ways over the years. They've helped me connect with other women with the same diagnosis, helped me ask for a second opinion and supported me to share my story.

"As a patron, I'm hoping to lend my assistance wherever and whenever Ovacome needs me to help. We all want earlier diagnosis which usually means a better prognosis, and I'll do all I can to help Ovacome achieve their mission."

You can read more about Adele's experience with ovarian cancer by visiting the website: **ovacome.org.uk/ovacome-patrons**

Lady Adele Sewell MBE

> "**Ovacome has helped me in many ways over the years.** They've helped me connect with other women with the same diagnosis, helped me ask for a second opinion and supported me to share my story."

Our fantastic fundraisers!

The Teal Machine does it again!

Last year, the Magnificent Six: Phil, Stu, Steve, Dan, Simon and Tux, powered from London to Paris in 24 hours to raise funds for Ovacome. This summer, the team was determined to pull off an even more spectacular feat to support our community. Their challenge of choice: Chase the Sun. The team of six rode 180 miles across Italy, from Rimini on the east coast to Tirrenia in the west, all before sunset on the summer solstice! They were spurred on by the memory of their dear friend Debbie Baldwin, a lawyer, London Ambulance Service volunteer, and passionate advocate of ovarian cancer awareness, who died from the disease at just 52 in 2021.

"It was tough to be honest", reflects Phil, "but together we did it! We were amazed by the level of support we received. Another cyclist told me we were a 'turquoise machine'. I didn't have the energy to tell him it's teal!".

They raised a spectacular £50,000 for Ovacome's services, bringing their total raised to £92,622 over the past two years.

Phil and the gang weren't the only ones carrying Debbie's legacy forward in 2024. Just a couple of weeks before the epic cycle, the third annual Debbie Baldwin Gala took place in London's Docklands.

Organised by Debbie's loved ones including her husband Prav and best friend Angela, the evening was a medley of delicious food, a brilliant auction, 80s classics, dancing and laughter. This year, the event raised an extraordinary £21,599 and in total, over the past 5 years, £166,391 has been raised in Debbie's honour.

A walk to remember

Steve Eckersall and his oldest friend, John, took on the colossal challenge of walking 542 miles from St Jean Pied de Port in France, across the Pyrenees to complete the hallowed Camino de Santiago Frances trek, finishing in Cape Finisterre in Spain. Steve walked to raise vital funds for both Ovacome and Cruse in memory of his wife Siobhan who died from ovarian cancer this February.

"Before Siobhan became ill, we'd always thought about doing the Camino" Steve explains. "After the funeral, I knew I had to do something for her, for me and for Ovacome. We just kept putting one foot in front of the other, covering up to 30km every day, for 19 straight days. It was harder than I can describe", reflects Steve. "I had done some preparation, but it wasn't enough!" Steve's top tip for crossing an entire country on foot? "You just carry on"!

With the help of his daughter Olivia, and an outpouring of support from his loved ones, Steve raised £2,432.50 for Ovacome. This brilliant sum could allow us to raise awareness of the signs and symptoms of ovarian cancer amongst 52,125 people! Steve, your determination will touch the lives of so many. Thank you for your amazing perseverance.

"I would recommend fundraising to anybody" says Steve. "If you are a bereaved family member it gives you time to think. Raising money makes your beloved's death mean something – you just won't give in".

Read the whole story on Steve's blog at www.steveswalkofhopeforsiobhan.com

The biking bug is in the air!

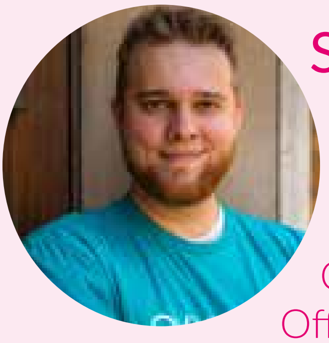
Janet Kerr from Croydon and her wonderful family – John, Matt, Emma and Bob – also took to their bikes this summer at the Ford Ride London 2024, a 100-mile route. "We wanted to raise funds for Ovacome and show our appreciation because of the fantastic support the charity has provided", Janet explained. After being diagnosed with advanced ovarian cancer last autumn, Janet found our support line "invaluable" for helping her understand different ovarian cancer treatment options and said our Travelling Abroad booklet was "really helpful" when faced with the complexity of travel insurance before a family holiday.

Apart from Janet, none of the family were regular cyclists, but their training and sheer determination paid off! "I managed seven miles, but they were the best seven miles I have ever cycled!" Janet reflects. "John kept me company, but the others cycled the full course! The experience was just magical."

Through their stellar efforts, Janet and her family raised a staggering £6,019! That will help us to answer more calls on the support line and provide information booklets to more people who need them.

If you're inspired, you can make a difference by doing a challenge or hosting a community event for Ovacome. To get involved, email **fundraising@ovacome.org.uk**

Say *hello* to the Ovacome team



Sam Wilson

Sam will work within our comms team as a Communications Officer. He's based in Birmingham and has prior experience of working within the charity sector, particularly in developing case studies and sharing people's stories. Sam hopes to bring his experience and passion to Ovacome, saying **"Ovacome is a hugely important and respected organisation and I can't wait to get to work. I've been really struck by the positivity and welcome I've received so far and look forward to getting to know the Ovacome community more."**

Holly Hunt

Holly is a volunteer at Ovacome, she is a recent graduate of Architecture from UCL. She is originally from Leicestershire but has been living in London for the past three years while studying.

Holly loves reading, art and design, sports and socialising. Holly says: **"Ovacome has always been special to me. It helped my mum and our family a lot when I was little, and now I am glad to have the opportunity to give back".**

Know a company that could help?

There are many ways that companies can support our work, from match funding employees' fundraising activities, donations for raffles or partnering with us as their charity of the year.

These are all great ways to help raise much-needed funds and awareness. If you or someone you know works for a company, put Ovacome forward to support.

To find out more, email Lee at L.priestly@ovacome.org.uk or call 0207 299 6651.

Are you getting ready for OCAM?

March 2024 is Ovarian Cancer Awareness Month (OCAM).

Let's all come together during OCAM to help raise funds, as we know that life changing support for those diagnosed with ovarian cancer is vital.

"Ovacome and the Ovacome community were a godsend and an anchor." ***- Tracey***

There are many wonderful ways in which you can raise funds for Ovacome, like tea and coffee mornings, taking on a walking or cycling challenge and setting a distance goal with friends and family, or signing up to one of the many challenges across the UK on our website. Go big and organise a large event like a gala or music evening with friends. Or have a birthday party fundraiser and request donations instead of presents.

"Thanks to Ovacome, I've been able to meet other women with ovarian cancer, which helped to take away the isolation that ovarian cancer so often brings. Because of this, I've been fundraising for Ovacome for the last 11 years and it is such a joy to raise funds for such a worthy charity." ***- Adele***

The wonderful **Christina Cornberg** at her GNR cake sale in April 2024!

We are here to help you with your ideas. Get in touch as we can't wait to help you develop your ideas into wonderful fundraising experiences. **Please email fundraising@ovacome.org.uk or call Imo on 07767 619462.**

You can ***double*** your impact with The Big Give!

The Big Give is a match-funding campaign, meaning your donations made to us, via The Big Give website from 12 noon Tuesday 3 December to 12 noon Tuesday 10 December 2024, will be doubled. If you donate £25, we will receive £50 at no extra cost to you. If you are a UK taxpayer, please do not forget to tick the Gift Aid box as your gift will be worth 25% more.

You will be helping others who have been diagnosed with ovarian cancer and we can't do it without you.

"I will always be so grateful for the call I had with Cathryn on your helpline when I was in the depths of being ill and very scared about what was going on with my body... she was really amazing." ***- Tori***

What could your donations provide?

£28 would provide an hour of one-to-one specialist support for someone affected by ovarian cancer.

£84 would cover the cost of running one health and wellbeing workshop for 18 people.

£142 would cover the cost of running an in-person support group session for 12 people.

How do I donate?
If you'd like us to remind you of the date, register at **ovacome.org.uk/big-give-2024** or email **fundraising@ovacome.org.uk** and we will email you when the campaign goes live. Or call us on **0207 299 6654** and we will call you when the campaign starts and talk you through how to donate.

Patient voice research triumphs at the British Gynaecological Cancer Society's Annual Scientific Conference

In the last edition of this magazine, we featured granulosa cell tumours (GCT), one of the rarer forms of ovarian cancer, and hinted that we'd be able to update you on our work to improve patient care for people with GCT come the autumn.

Working with GCT Survivor Sisters UK, we surveyed 111 members to ask about their perspective of being diagnosed with and monitored for GCT. For many with this rarer form of ovarian cancer, Inhibin A and B and AMH testing are the most effective tests. We were delighted to co-present a poster about the research at the British Gynaecological Cancer Society's (BGCS) Annual Scientific Conference.

At the conference, Ovacome staff were joined by Linda Langdale and Suzanne Love, who had both been involved in the research. It found a wide variation in patient experience across the UK and delays in receiving results for Inhibin markers, which increases anxieties. In some instances, patients are self-advocating or self-funding tests.

At the end of the conference Suzanne said "It's been a fantastic couple of days and a real opportunity to have deeper conversations with clinicians outside of their usual setting. This research has given us scientific evidence to campaign for small changes which will make a huge difference."

This patient-focused research contributed to changes in the British Gynaecological Cancer Society (BGCS) ovarian, tubal and primary peritoneal cancer guidelines: Recommendations for practice update 2024, which now includes a section on follow-up of sex chord stromal tumours and suggestions on the use of Inhibin B and AMH blood tests if available.

Suzanne continued, "It's amazing to think this work had an impact on the BGCS guidelines, it's something that we're really proud of.

"Since the change in the guidelines, I have successfully had AMH added as a tumour marker to my blood test panel. This is a real step forward for me as my Inhibin blood tests are in range and I have no symptoms, but my CT scan following my last surgery is showing a nodule. If my AMH is in range I'm hopeful I can delay another surgery for a bit longer."

And what's next for the group? Suzanne says "We aren't planning on stopping our work here! Care at the major centres is improving, but we want to see the same level of care for everyone, no matter where you are diagnosed and treated. We are also looking at worldwide groups to gather data about whether radiotherapy could work as a treatment option."

This research shows how your voices can lead to real change. We're looking forward to continuing our work with GCT Survivor Sisters UK and we want to work with the NHS to start improving testing facilities for those with GCT.

> "It's amazing to think this work had an impact on the BGCS guidelines."
> ***- Suzanne Love, member of Ovacome and GCT Survivor Sisters UK.***

Unlocking expertise

One of Ovacome's unique advantages is that we work closely with many experts. They kindly share their knowledge, experience and networks so that our support team is able to answer your questions and our information contains the most up-to-date information. Many of you will have heard about Ovacome via your clinical team.

Here, we highlight how we work with experts, and how you can help make sure more know about Ovacome.

Expert Advisory Panel

Over 30 experts sit on Ovacome's Expert Advisory Panel, each with their own area of expertise. They all kindly give their time for free. As you would expect, it has medical and clinical oncologists and surgeons, but we also have dieticians, occupational therapists, pharmacists, clinical nurse specialists and psychologists. See a full list of members here: **ovacome.org.uk/expert-advisory-panel**

Specialist Webinars

Ovacome runs specialist webinars on topics that you request. Most sessions are recorded and uploaded to YouTube for you to watch back. **Visit youtube.com/@OvacomeCharity**

Talks at events

If you attend our in-person events, you'll likely hear a talk from a leading clinician in your local area. We were joined by Professor Sudah Sundar in Birmingham earlier this year (see page 12) and Mr Mohamed Mehasseb in Liverpool in January.

Reviewing materials

Our 50 information booklets are re-viewed by experts. If you look at the back of each booklet, you'll see which expert has been involved in its production.

Enhancing Patient Experience (EPE) and Survivors Teaching Students (STS)

These two projects increase the knowledge and understanding of current and future clinicians, where your voices are front and centre. STS is aimed at medical students, and EPE gives those working in gynaecological cancer practical tools to reduce the barriers some patients face when accessing treatment.

Working alongside Ovacome on patient research

We are often asked by experts and researchers to work alongside them. Over the page you'll have read the difference this can make to your care. We have a few more exciting projects in the pipeline focusing on diagnosis and treatment that we'll be able to tell you more about soon!

How can *you* help?

We're developing new packs, and you can help by distributing them to your clinical team. You will be helping others with ovarian cancer get support and information earlier, when they most need it. **If you'd like to be involved, get in touch by emailing ovacome@ovacome.org.uk.**

> Your website has been amazing - the best resource for information on Borderline Ovarian Tumours I could find. I even watched an hour-long webinar on your site, which was hugely useful. Thank you.
> ***- Jennifer, Ovacome member***

Christmas tips

With the holiday season approaching, contacts to our support channels often talk about the anxiety this time of the year brings. In this article, we've summarised some of the resources we have available on our website.

Managing with a stoma

Barbara Milleret, specialist stoma nurse and member of Ovacome's Expert Advisory Panel, often joins our online stoma group, a space for anyone living with a colostomy, ileostomy or urostomy to chat with others and share advice and experience in a relaxed, informal environment.

Food can play a major role in the holiday season. We may eat richer foods than usual, our meal patterns can be irregular, and our food intake often increases. Last year, at the request of the group's members, Barbara ran an online session about coping with a stoma during the festive period. We've compiled some of the highlights of this talk for this magazine article.

Barbara recently joined us for a webinar on ovarian cancer surgery and stoma care which you can find a recording of on our YouTube channel: **youtube.com/watch?v=iLSt0gvfm2g**

Needing to change or empty your pouch more frequently

Changes in diet may mean that you find you need to change (for a colostomy) or empty (for an ileostomy) your pouch more often than you would usually.

Tips:

- Have some drainable pouches to hand in case of an upset tummy or diarrhoea, giving you the option of emptying instead of changing so regularly.
- Make sure you're well stocked with stoma supplies, to account for any change in output.

Eating new foods

It is always advisable when introducing a new food to your diet to have a small portion first – try a small portion, to see what effect it has on your stoma function. Everybody is different in their tolerance and response to foods.

Taking care when chewing

Try to chew all food well to help aid digestion – particularly those foods that are high in fibre (see below).

Watch out for food that's high in fibre

Foods that are high in fibre may produce more wind and looser stools. Foods you may encounter at Christmas are dried fruits, nuts, coconut, citrus fruits, celery and sweetcorn. Spicy foods and bamboo shoots (often in Chinese foods) can also cause erratic or faster output. Generally anyone with an ileostomy will be advised to avoid these foods and it is not recommended that you eat the above foods with an ileostomy.

Some people with a colostomy can eat all these foods in moderation. You tend to run into problems if you eat a lot of these foods at any one time. Watch out for how many mince pies or how much Christmas cake and pudding you are eating!

Some foods to watch out for

- **Brussel sprouts and other green veg like cauliflower, broccoli and cabbage** are often problematic and can cause excess wind and odour.
- **Beetroot** – this can colour output red and easily be mistaken for bleeding.
- **Stilton and similar cheeses** can increase odour from your output.
- **Fizzy drinks** can increase the amount of wind so your stoma will be more vocal, or your pouch might balloon.
- **Excess alcohol** will affect you just as it affects people without a stoma. It will make you pass more urine, which can dehydrate you, especially if you have an ileostomy.

Anyone diagnosed with ovarian cancer and who has a stoma is welcome to join the online monthly stoma group. It runs every third Wednesday from 11am to 12.30pm on Zoom. Visit our website or call the support line to book your place.

Diane's tips

Back in 2019, Ovacome member Diane shared her thoughts around how to manage a Christmas which might be more difficult than usual, in two blog posts. Here, we've shared an extract.

For many, this time of year is tinged with sadness, fear and anxiety. I am one who lives with that uncertainty because although I'm stable now, previous years were a different story. Each Christmas has felt different depending upon what was going on in relation to my disease.

Here are a few things that have helped me:

- **Don't hide your feelings away too much.** When feelings are shared and acknowledged it allows everyone to support each other

- If your family traditions are simply not achievable maybe you could **try to create new ones.**

- Christmas is not just confined to one day so don't try cramming it all into twenty-four hours. **Space out the festivities to a more manageable itinerary.**

- **If someone else is cooking, let them know what you feel you could eat.** There is no reason why you can't retire to have a rest away from everyone while they are eating their meal. Equally, if you want to sit with everyone at the table with a small amount of food or just a drink that is absolutely fine too. There are no rules so do what you need to do.

- **Plan and prioritise periods of rest,** have somewhere that you can retreat to or let family know that you might need to leave sooner if you don't feel well enough.

- If you are undergoing treatment which compromises your immune system, **ask that visitors stay away if they have a cold or other infection.**

- **There is more to Christmas than gifts and cards.** If you can manage them, then do so but don't let it be to the detriment of your health or precious time. One year, I did all my Christmas shopping with a nature charity and purchased bird feeders and bird seed.

- **Make sure you have enough medications to cover the holiday period** and if you require incontinence pads or stoma bags etc check you have enough of those too. Create a list of telephone numbers that would be useful should you need help or advice.

Diane runs and presents the podcast *"Living with Ovarian Cancer"*. Listen on all major platforms including here: **https://anchor.fm/diane-evans-wood.**

Read Diane's full blogs on the Ovacome website:

ovacome.org.uk/Blog/last-christmas-part-1
ovacome.org.uk/Blog/last-christmas-part-2

Have you been to one of our Health and Wellbeing Days?

Have you been along to one of our Health and Wellbeing Days this year?

We've been making it our priority to come out to your local communities. On our road trip we've made connections with local charities and healthcare professionals and given you the opportunity to come together, as well as take home practical tips to look after your health and wellbeing during diagnosis, treatment and beyond. These events are something we provided regularly before the Covid-19 pandemic, and it's been an absolute pleasure seeing so many old friends and new faces.

We've had fabulous feedback about our events, so we're not intending to stop anytime soon, with another full calendar for this year. Sam, the newest member of our communications and engagement team, attended the Birmingham Health and Wellbeing Day earlier in the year and wrote this diary entry so that those who haven't been before have an idea about what to expect.

Shots from Birmingham Health and Wellbeing Day

Written by Sam Wilson

Birmingham Health and Wellbeing Day Diary

Having only recently joined the team at Ovacome, I was filled with equal amounts of intrigue and excitement ahead of my first Health and Wellbeing Day. It was a great chance to meet some of you in person, and understand why these days are held in such high regard.

10AM:

Our doors open at 10am and it's great to start welcoming members, making some introductions, as well as making sure everyone's cup of tea is full for the first part of the day.

10:30AM:

It was then time for our first presentation of the day – a talk from Professor Sudah Sundar, one of the most influential researchers into ovarian cancer. She has worked tirelessly to find out more about the disease and inform others, recently completing her term as the President of the British Gynaecological Cancer Society (2019-2022), the first woman gynaecological oncologist to be elected to this post. Given her experience and knowledge of ovarian cancer, I was very excited to hear Professor Sundar's presentation. She gave an incredibly insightful talk on the ways that ovarian cancer can be detected earlier, while also presenting some of her latest research surrounding ovarian cancer.

11:15AM:

After the first talk, it was time for a well-earned refreshment break. It was fantastic to see attendees have the chance to chat to Professor Sundar and there were lots of conversations in the room about individuals' experiences and what parts of Professor Sundar's talk they'll take away. I found her insight into new means of testing for ovarian cancer particularly interesting

11:30AM:

Next up we heard from Catherine Spencer, Lead Macmillan CNS in Gynae Oncology at The Pan Birmingham Gynae Cancer Centre, who gave a talk on 'Holistic Needs Assessments'. Catherine explained that a Holistic Needs Assessment is a discussion you have with someone from your healthcare team, starting with filling in a small sample of questions. I learnt that these discussions can be vitally important as they let you talk through any manner of concern you might have – be it physical, emotional, financial, spiritual or anything else.

12:15PM:

Before lunch we had a Q&A session followed by some much needed food and drink to fuel us for the rest of the afternoon. Lunchtime was a great period to make some new connections and discuss the day so far but also offered the chance to recharge and collect thoughts.

1:45PM:

Our first session after lunch was delivered by Kris from Black Train Music. The 'live music for relaxation session' showcased a variety of piano pieces, exploring the power that music can have in facilitating inner peace and calm. It was interesting to see how powerful music can be and think about the different ways we listen to music and process it.

2:40PM:

Time for our last quick refreshment break!

3:00PM:

The final talk of the day was delivered by Angela Vigus, who is a local wellbeing practitioner and palliative care therapist. She shared some practical advice and tips on how you can best prioritise your self-care both during and after treatment. This talk looked at self-care in a different way than I'd ever considered, so I found it very insightful listening to Angela explain some of the simple yet effective ways we can all prioritise ourselves and our wellbeing.

4:00PM:

And that's a wrap!

SAVE the DATE

2024-2025 in person events

Friday 11 October 11am-3.30pm Bristol

Saturday 26 October 11am-3.30pm
Southampton

Saturday 16 November 11am-3.30pm
Bournemouth

Tuesday 26 November 11am-3.30pm
Bath

Tuesday 28 January 10.30am-4pm
Liverpool

Saturday 15 February 10.30am-4pm
Birmingham

Saturday 29 March 10am-4pm
London Members' Day

How do I sign-up for an event?

Don't worry, it's easy! All information is online and if you're comfortable following these steps, go ahead. If you'd prefer, you can book over the phone by calling 0207 299 6654.

1. First, head to ovacome.org.uk and find the 'Get Involved' tab on the banner.
2. Click on 'Come to our support groups and events'.
3. Once you're onto this page, simply scroll down and find the Health and Wellbeing event you're looking for and click on the link.
4. On this page you'll find information about the event and a booking form to book your place.

Booking is usually open eight weeks in advance of the event date.

You can also follow us on social media for a link direct to the booking page.

Our 2024-25 Programe of Events has generously been supported by the National Lottery Awards for All.

NAVIGATING INHERITED RISK

In the last edition, we launched new information booklets about ovarian cancer and genetics, as well as a series of specialist webinars related to increased inherited risk.

In this article grandmother and granddaughter Simone and Leah, who both have a BRCA1 gene change, share their stories.

Simone

My cancer 'journey' started in early 2018. I'd returned from Canada, where my sister had died of breast cancer, and I decided to go to the doctors with a few worries I had.

I told the doctor I was experiencing discomfort in my vagina, had a feeling of bloat and could feel a lump. Ovarian cancer wasn't discussed, instead IBS and a prolapsed bladder were diagnosed as the cause. With a busy work life and caring responsibilities, I didn't return until early 2020 to say I was worried about ovarian cancer because of my family history.

Although my bloods were clear, a vaginal ultrasound, scan and biopsy indicated that I had a growth on my left ovary.

A few weeks later I started my chemo. I couldn't wait to start, I had decided that however it made me feel, I would see it through. I coped well with the chemo, and after only my second cycle the oncologist called me to tell me the tumour had already shrunk enough for me to have surgery.

By late September, I was in hospital for surgery and while initially it seemed all had gone well, they found my bowel had been affected. I didn't need a stoma, but I was in hospital for nearly five weeks waiting for my bowel to sort itself out. It was a pretty grim time, it was the middle of the pandemic and my daughter and youngest son were only able to visit once each.

I was relieved to get home and then back to chemotherapy. Just before Christmas I got away to Amberley Castle with my mum for a few days. It was her I felt for throughout. My brother had died many years before, and now she was having to watch me go through the same treatment so soon after my sister.

I've been in remission for about three years now. I was told at one of my first appointments that my cancer was treatable but not curable. Once you get a cancer diagnosis, your whole world crumbles in front of your eyes. Nothing is ever the same again, there's never a minute of the day when you're not hoping and praying that it doesn't come back. I've only just recently started to feel like I'm back in the normal world and even looking to the future. but I'm so relieved that she didn't have to witness her third child die as well.

I have the BRCA1 gene change, so there's always the worry I might develop cancer elsewhere. My family have been checked, including my children, my niece and cousins. My second daughter, who is 48 has the gene change as well as her 28-year-old daughter Leah.

I'm much more open when talking about ovarian cancer now. I now run a community library, raising awareness and funds for Ovacome. A woman recently visited the library who said that she'd had stage 3 ovarian cancer 20 years ago, and was fighting fit! It gave me hope that there are some survivors and that maybe I might be one of them. With constant research, and improved medication such as PARP Inhibitors, as well as better awareness among doctors of the symptoms, I think there is a battle worth

Leah

Though I was born and raised in the UK, for the past six years I've been living in New Zealand with my Kiwi husband.

Unfortunately, aged 20, I became unable to have children because of a medical mistake following an assault. I can get pregnant, but pregnancies embed in my fallopian tubes. Since then, I've had two ectopic pregnancies in 2018 and 2020.

Around the time of the second ectopic pregnancy, my grandmother Simone was in the UK undergoing treatment for ovarian cancer, and discovering she has the BRCA1 gene change. My mother also is BRCA1 positive. She kept this information from me for a little while. I was not in a good place, and it was fair judgement.

After she told me in 2021, I found out that I also have the mutation. I can't repeat the words I said upon hearing that.

I felt like I was presented with a dilemma. Because of my fertility challenges I'll need IVF to conceive but is it right to bring a baby into the world, knowingly putting them at risk of inheriting the mutation? How could I justify that?

But wait… There's a test. Preimplantation Genetic Testing of Embryos for BRCA Mutation Carriers*. Doctors can test the embryos before implanting them. The fact that this exists, changes everything for me. It's my little light when I'm in my darkest place.

In January 2024 doctors found a cyst on my right ovary and it will need removing. It's the safest option but again will lower the chance I have at becoming a mum. When everything seems bleak, I remind myself of this: for me, finding out I have the BRCA1 mutation has changed the way I receive medical treatment. As awful as it is, I'm so grateful I found out. It's given me the one thing that so many people don't have… time.

*In the UK this test is referred to as Preimplantation Genetic Diagnosis. More information about the test, availability and eligibility in the UK can be found by visiting the Genetic Alliance UK: **https://geneticalliance.org.uk/.**

Our support line can talk to you about any questions or concerns you have about the increased inherited risk of ovarian cancer. **Call them on 0800 00 7054, lines are open 10am-5pm Monday to Friday.**

Liz Waters, Health Equalities Manager

ADDRESSING HEALTH INEQUALITIES IN OVARIAN CANCER

Across the UK, not everyone's experience of cancer is equal. Ovacome is committed to making sure that anyone affected by ovarian cancer can have the earliest possible access to diagnosis and treatment.

In the summer edition of this magazine, we introduced Liz Waters, who joined us in February 2024 as Health Equalities Manager. In this edition, we caught up with Liz and asked her to explain more about her work.

Liz, can you tell us a little bit more about your role? What does your typical day look like?

No two days are the same, that is for sure! Ovacome's goals for health inequalities are ambitious, and so that means that we have multiple projects on the go.

One day might involve talking to community groups so they have the knowledge and information they need to increase knowledge of ovarian cancer where they work, and another day might be spent looking at Ovacome's own support services to make sure they are as accessible as possible to anyone who needs them.

Which groups are you hoping to reach with this work?

Our work is deliberate and informed by research about who needs the most support. For instance, research tells us the likelihood of presenting with cancer at A&E is 50% higher in the most deprived populations than it is in the least deprived, so one of our target groups is those on a low income or living in poverty. Black and Asian people are less likely to recognise cancer warning signs, which is why translating our B.E.A.T signs and symptoms into community languages is so important. Many of our members will know that one area of focus for Ovacome is on the rarer forms of ovarian cancer. This work makes sure that those with a rarer diagnosis feel like they have the information and support they need to navigate their way through diagnosis and treatment.

In addition to these groups, our research has flagged the following communities as those which we should target: people under the age of 45 and over the age of 70, people who are digitally excluded or with low levels of literacy, those who are rurally isolated and not being treated at a major centre, people with disabilities other than cancer, those from the LGBTQ+ and Gypsy, Roma, Traveller, Showmen and Boaters (RTSB) communities as well as refugees.

But how does it work in practice?

One of the most important aspects when working with groups who feel marginalised is having their trust. At Ovacome we might have ovarian cancer knowledge, but we don't always have the trust of the communities we're trying to work with. For that reason, my work is about building relationships with other organisations who already have connections with those who might need Ovacome's help. By working in partnership, we not only gain insight into the barriers which their specific communities face, but we also increase our engagement.

The second thing we need to do is make sure that when we do find someone who needs our help, we're able to give them what they need. That's why our support line and selected information are available in different languages, why you can request a BSL translator at any in-person or online event we run, and why we offer bursaries to any member who would struggle financially to access our support services.

The final piece of the puzzle is our work to increase the knowledge and understanding of clinicians, in which the voices of patients themselves are front and centre. The Survivors Teaching Students programme is aimed at medical students, and Enhancing Patient Experience gives clinicians working in gynaecological oncology knowledge of the barriers underrepresented groups in their local area might face, and practical tools to reduce inequitable access.

If you'd like to learn more about this work or be involved, contact Liz by emailing l.waters@ovacome.org.uk

OVACOME LAUNCHES EASY READ BOOKLETS

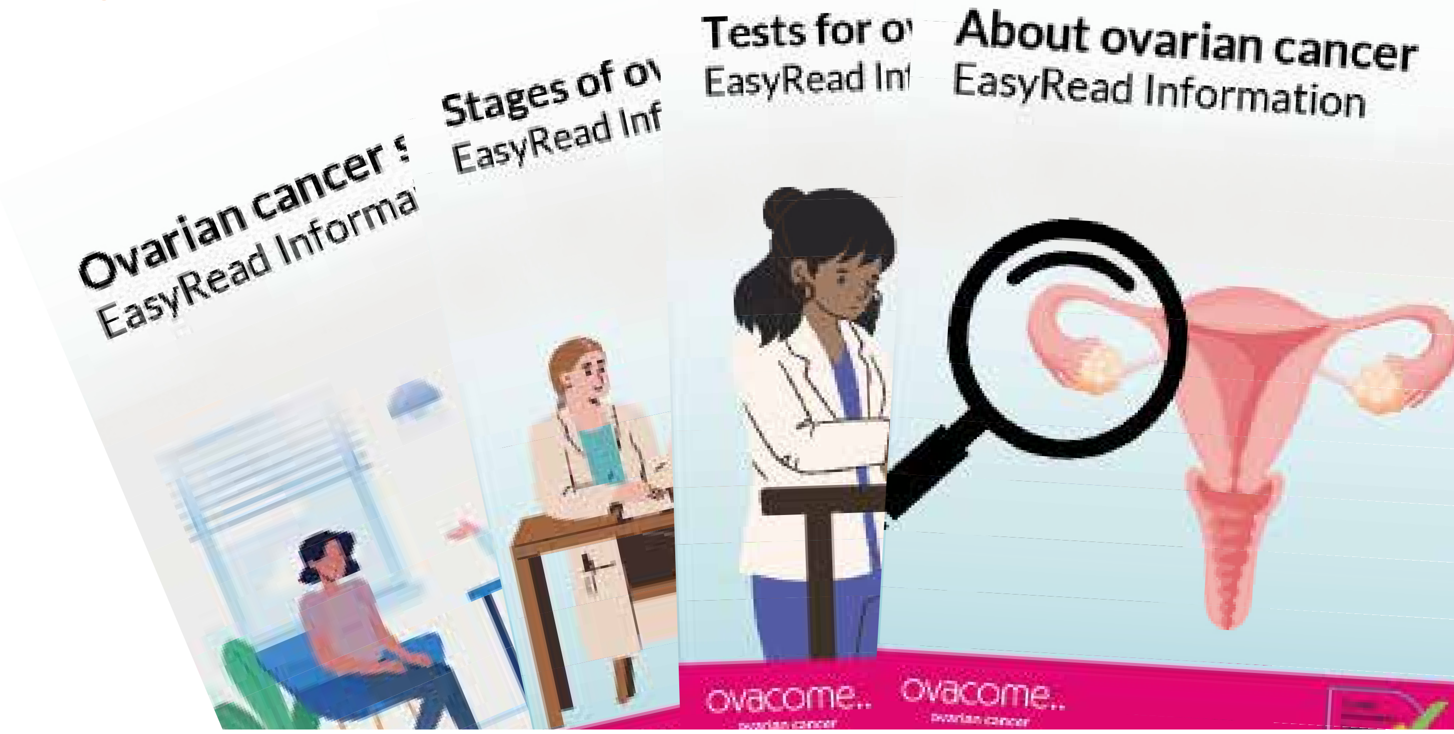
Our suite of information booklets jumped from 46 to 50 with the introduction of four easy read booklets.

These booklets use simple words and clear pictures to make information about ovarian cancer easier to understand.

They help people with learning difficulties and autism understand their ovarian cancer diagnosis better.

We worked with charity Generate to develop these booklets. Generate was founded in 1972 to make sure that people with learning difficulties weren't isolated in their local community.

They can be downloaded online at ovacome.org.uk/easy-reads, or if you know an organisation or individual who would benefit from a printed copy, request a copy via the same link or by calling 0207 299 6654.



Seasons greetings

The nights are drawing shorter, we're all starting to retreat indoors and the festive season is just around the corner. Ovacome's shop has you covered with festive greeting cards for your friends and family, some beautiful, handmade decorations and items to keep you wrapped up warm throughout the winter months.

Browse our products at: ovacome.org.uk/shop

1

HANDMADE FINGERLESS GLOVES

Pick up a pair of these handmade fingerless gloves, keeping your hands warm, but still allowing you to do those fiddly jobs – finding change in your purse or using a touch screen.

Priced at: £4.50

2

OVACOME HOODIE

This fleecy hoodie will keep you warm while reminding others of the B.E.A.T. signs and symptoms of ovarian cancer. Available in sizes S – XXL.

Priced at: £25.00

3

HANDMADE TINSEL

Decorate your home with these handmade tinsel decorations, available in blue, white, dark gold, green, white and pink as well as red and silver. The baubles have been lovingly crafted by one of our talented members.

Priced at: £2.50

4

FESTIVE GREETINGS CARDS

Our festive season's greetings cards are now available to order. Visit the online shop or use the order form within this magazine to get yours before they run out. This year cards are available blank or containing the message 'Season's Greetings and Best Wishes for the New Year'.

Priced at: £4.95

OTHER BRANDED ITEMS

And don't forget, we also have some smaller branded items for you to show your support for the ovarian cancer community as you're going about your day-to-day life. Pick up a trolley coin for use at the supermarket, a new enamel pin for your coat lapel or a pen to write those letters to Santa!

5

OVACOME PEN

Priced at: £1.50

6

OVACOME TROLLEY COIN

Priced at: £1.50

7

OVACOME PIN

Priced at: £1.50

Sue’s Story

As this magazine lands on your doorstep, we’ll have just said goodbye to September, Gynaecological Cancer Awareness Month. During the month we asked you to share your symptoms, using our B.E.A.T signs and symptoms campaign.

Statistics tell us that **66 per cent of people hadn’t heard of ovarian cancer, or knew anything about it, prior to their diagnosis.** Thank you to everyone who helped us to increase knowledge and information about the disease during the month, so that anyone who does experience signs and symptoms knows what to look out for and seeks support from a GP as soon as possible. **In this postbag, Sue shares her experiences.**

My symptoms were all very subtle. I was feeling tired, needed to pee more often and with some urgency which I put down to my age. When I ate, I felt that the food wasn’t going down properly and sleeping on my front wasn’t comfortable anymore. I thought something I was eating was upsetting me.

I first visited my GP about something completely unrelated. As I hadn’t been for a while, she sent me for a blood test. Before returning for the results, I noticed a hard mass on my left-hand side. To start with, I assumed it was supposed to be there, but my husband’s stomach didn’t feel the same.

Back at the GP I was given a clean bill of health. My cholesterol had never been so low “Well done Sue,” said the GP. But as I left, I mentioned the lump in my stomach. I was sent for an ultrasound and panic set in when it was followed with a CT scan and another blood test. “Could it be ovarian cancer?” I asked. She replied, “Absolutely not.”

The blood test put my CA125 level at 6,500 and a week later I was at 6,500 and a week later I was diagnosed with stage 3c high-grade serous ovarian cancer.

My doctor said, “You have an aggressive cancer with an 80 per cent chance of recurring in the next two to four years”. I never dreamed I would be fortunate enough to see any grandchildren.

But roll forward the clock seven years and I’m living my life to the full. I still hold my breath for my test results at every six-month check-up, but if someone says “Would you like to go…” I’m there before I even know where I’m going!

Meeting other women with ovarian cancer has changed a lot. They have given me confidence and support and showed me how to go on and enjoy my life, even though the future may be uncertain. I’ve walked over the O2, been up the Eiffel Tower and even took part in a cancer survivors’ fashion show!

And now we have four grandchildren. My aim was to see our first start school, that was a very proud nanny day, I can tell you!

recognise the

B.E.A.T.

signs of ovarian cancer

B is for **BLOATING**
that doesn’t come and go

E is for **EATING** difficulty
and feeling full more quickly

A is for **ABDOMINAL**
and pelvic pain you feel most days

T is for **TOILET** changes
in urination or bowel habits

Could you help us raise awareness of the signs and symptoms of ovarian cancer?

Order an awareness pack by visiting **ovacome.org.uk/b-e-a-t** and display it in your local community.