AWARENESS MONTH
Ovacome spreads the message with tokens of support and love

GOING ON TRIAL
A leap of faith or golden opportunity?

TEAL TIPS
Manicure party bags for March fundraising

MEMBERS’ DAY
Leading oncologist talks on world class survival rates
It’s awareness month in March, the time that the spotlight is shone onto ovarian cancer and we pull together to shout about the symptoms of a disease which is often misguidedly referred to as the silent killer.

This year Ovacome will reveal some other misconceptions about the disease when we launch the findings of our biggest member survey to date, which we will use to help improve the services and treatment for women with ovarian cancer.

All will be revealed - and there will be some surprises - when we present the findings at Members’ Day in March. But in the meantime I would like to say a big thank you to all of the 418 women who took part in the survey giving us an ‘at the coal face’ view of living with ovarian cancer.

One of the areas the report looked at is accessibility to clinical trials. It’s something we are working on already with plans to bring out our own online clinical trial finder later this year. Again there’s much misinformation about trials, and on page 9 Dr Ros Glasspool gives guidance on their important role.

I look forward to sharing the results and meeting many of you at Members’ Day. And in the meantime I am sure I will see some of your faces in the press, sharing your story to help debunk the myths surrounding ovarian cancer, which can get in the way of that all important speedy diagnosis.

Louise Bayne, Ovacome chief executive.
'Because you are special to me' is Ovacome's big push for Ovarian Cancer Awareness Month: a campaign to raise the profile of the disease and to give women an opportunity to tell someone how important they are to them on social media and by gifting beautiful wooden keepsakes designed for the charity.

The idea of the campaign - #Because - is that women choose somebody close to them to share the symptoms of ovarian cancer by word of mouth and on Facebook and Twitter, directing them to Ovacome's website where they can find out more about the disease and how to make a donation (see box).

As part of its 20th anniversary celebrations, Ovacome has teamed up with personalised greetings cards business Hickory Dickory Designs to come up with a range of wooden keepsakes tying in with the #Because campaign. The made to order greetings cards and gifts are made from rosewood and are engraved with words of support and awareness.

Some of the keepsakes are designed for women who have ovarian cancer to buy one another as tokens of friendship and support. There are letter-shaped key rings with the words ‘You are never alone’ and the charity’s Freephone support line number engraved on them.

Also, business card sized plaques have the message ‘Ovacome is here to support you every step of the way,’ designed to fit into a purse and for the charity’s contact details to be readily accessible at all times, as well as a constant reminder of the love and support of the sender.

To spread awareness during March and beyond there is a circular key ring, a wooden plaque and two greeting cards with a wooden cut out of the ‘Because you are special to me’ and ‘Because I love you’ messages presented on a card, perfect also for Mother’s Day. They have Ovacome’s website subtly engraved onto them - so that women will have a contact to hand if over the years they become concerned about the disease.

Ovacome’s chief executive Louise Bayne says that the keepsakes will be sold throughout the year as part of the charity's 20 year celebrations. “We wanted to do something special for this awareness month to mark our significant anniversary and to reinforce that we are the longest serving charity in ovarian cancer, supporting women, their carers, friends and family,” says Louise.

“These keepsakes give women, whether they are Ovacome members or not, the chance to spread awareness of the disease and also to have the opportunity to tell someone special how much they mean to them,” she adds.

Each item costs £14.95, with Hickory Dickory Designs making a £2 donation on each purchase to the charity. The keepsakes can be personalised for an extra £1.

Get tagging
The idea of the #Because social media campaign is that when people tag friends, a mention is given to make a donation to Ovacome by texting OVAC00 followed by the amount to be donated to 70070, for example OVAC00 £3.

On longer posts friends should be directed to www.ovacome.org.uk and a mention should be given of the symptoms of the disease highlighted in the BEAT acronym: B is for bloating that does not come and go; E is for eating less and feeling fuller quicker; A is for abdominal pain and T is for telling your GP.

To order your keepsakes see page 15
Want to find out how some UK ovarian cancer treatment centres are reaching world class outcomes? Then come and listen to our keynote speaker Professor Gordon Jayson PhD FRCP (right) from The Christie hospital in Manchester, at Ovacome’s Members’ Day on Saturday 4 March.

The leading oncologist, a Professor of Medical Oncology at Manchester University, will present a report showing that patients treated at The Christie hospital in Manchester and Leeds and at UCL had a 45% better outcome than the UK average.

The study, he says, shows that the NHS is capable of "delivering international level outcomes", despite often being criticised for its ovarian cancer treatment results falling behind its comparable overseas counterparts.

At The Christie, he says, credence is given to phase I-III clinical trials, as well as laboratory research and investigator-led studies designed to improve the outlook for patients. Professor Jayson says he also likes to take a human-centred stance which focuses on patients’ wishes.

"This holistic approach means that we try to address psychological, psychosexual, genetic, nutritional and symptom management issues in addition to providing treatments for the illness," says the professor. "It is the combination of multi-disciplinary support, multiple existing and new treatment options and the privilege of looking after my patients that makes me so enthusiastic about my work," he adds.

Professor Jayson will also discuss research which suggests that not restricting the use of the maintenance drug Avastin to first line treatment could improve patients’ prognosis.

"Our research has identified the first test that can be used to work out when the drug is working and when it stops working. By using this test our studies have also suggested that we should use these drugs more than once if we are to improve the future for our patients."

- Also giving a talk - on ‘Cancer Genetics - the Importance of knowing’ - is Dr Angela George, (left) a consultant in oncogenetics and the clinical lead for the cancer genetics unit at The Royal Marsden. Dr George’s talk will discuss the main cancer genetic syndromes that include ovarian cancer and The Royal Marsden’s programme of routine genetic testing in cancer management.

She will also cover the treatment implications of genetic results and developments in ovarian cancer treatment based on genetic alterations.

- Also on the podium will be independent researcher Annie Gilbert, (right) presenting the results of Ovacome’s much anticipated patient survey.

Annie thanks all 418 women for participating and says there are some improvements while some things have become worse since the original 2006 audit.

Where it’s at

Date: Saturday 4 March, from 10.30am to 4pm.

Everyone is welcome, with a guest, and you can book your free place by calling 020 7299 6650.

Notice of AGM

Ovacome’s annual general meeting (AGM) will be held after the conference at 4pm and is expected to last for 30 minutes.

Attendance is for Ovacome members only and by notification at least five days before.

Any motions which are to be raised must be made by Ovacome members in writing together with a seconder, who is another member of the charity and must be in the hands of the chair of trustees at least 14 days before the AGM.

If you would like to attend please contact 020 7299 6654 to register.

To view Ovacome’s accounts visit www.ovacome.org.uk/about-us/annual-reports-and-agm-notice/

You can watch Members’ Day live from your home by finding ‘Ovacome Charity’ on YouTube. To get involved in the day tweet us using hashtag #MD2017
TEAL AWARENESS

Ovacome is delighted to have teamed up with Barry M again for this year’s Teal Tips awareness month activity, in which we ask members to wear striking green/blue nail polish during March as a conversation opener to talk about the disease.

Until the end of March, Barry M will donate £2.50 to Ovacome for every £4.99 bottle of this year’s Teal Tips, ‘The Way You Make Me Teal’ Sunset Gel Nail Paint, bought online from www.barrym.com/product/Sunset-Gel

And to help members celebrate Ovacome’s 20 year anniversary, it is also providing party kits for manicure fundraising events, containing the Teal Tips nail paint, a cuticle oil, a basecoat/topcoat, a nail file and a corrector pen in a Barry M ‘mani’ bag. There are 20 to give away to the first members who contact the office committing to raising £50.

The bags also contain Ovacome’s awareness material to hand out at your event with its easy to remember BEAT messaging of the main symptoms: B is for bloating that does not come and go, E is for eating less and feeling fuller quicker; A is for abdominal pain and T is for telling your GP. BEAT material is also available to anyone wanting to get involved in Ovarian Cancer Awareness Month and beyond, perhaps with our ‘Adopt a...’ year round initiative (see box).

To help keep your nails a talking point, this year’s Teal Tips gel-like varnish has a base coat built in and by applying a Sunset Gel top coat it lasts for days, giving the appearance of pro salon nails, says Barry M. “Go bold and wear it as a statement hue or take inspiration from Jeremy Scott and Novis’ SS17 showcases and go dotty as you pair with a nude or pastel base,” says its marketing manager Caroline Dawe.

Adopt a...

Ovacome’s ‘Adopt a...’ campaign in which members choose a public place to keep sourced with awareness material about the signs and symptoms of ovarian cancer, is gathering momentum.

Our main team member is Alan Sanderson, who lost his wife Yvonne to the disease in 2014. Alan has been distributing awareness leaflets to supermarkets, pharmacies, GP surgeries, estate agents, physiotherapy clinics, hospitals, universities and libraries all across Bristol, Clifton, Somerset, Weston-super-Mare, Gloucester, Devon and South Wales. Whenever he goes out, he says, he takes leaflets with him.

If you would like to join our ‘Adopt a...’ team contact Lee Priestly 020 7299 6651.

HELLO FROM ANNA

“I’ve been with Ovacome since the start of November and am really enjoying my role as support service manager and getting to know Ovacome members.

“I staff the support line from 10am to 5pm and I’m happy to discuss all aspects of ovarian cancer with anyone affected, including friends and family. And I can also be contacted via email at support@ovacome.org.uk.

“I help with the administration of the HealthUnlocked My Ovacome forum at https://healthunlocked.com/ovacome. This is an online space for women with ovarian cancer and their friends and family to support one another, but I will join in the conversation sometimes with information I think would be of interest to the community.

“Coming up, I’ll be working on the Ovacome clinical trials finder, which will make it easier for women to pinpoint clinical trials they may be eligible for.

“I look forward to meeting more of you at Members’ Day!”
Ovarian cancer survivor Adele Sewell (right), says a few words about the eighth Tea with Ovacome event taking place on Saturday 11 March this year, which sold out within days of the 200 tickets going on sale.

“When my daughter and I first came up with the idea of holding an afternoon tea at the May Fair hotel to raise awareness about the signs and symptoms of ovarian cancer, and to raise funds for Ovacome, we never expected that seven years later it would still be going strong. We just did not look that far ahead and quite frankly I did not think that I would still be here to see it happen, as I had been diagnosed with stage 3c ovarian cancer in September 2007.

"None of this could have happened without the support of family, friends, acquaintances and very often, complete strangers, who just wanted to help. There is a lot of love and warmth and generosity in the world.

“As a result of Tea with Ovacome, £125,000 has been raised for the charity - £51,400 from the afternoon tea event and £73,600 from the special dress that Apricot now makes each year exclusively for Ovacome (see page 7).

“This year we have a line-up of 11 models, most of whom will be taking to the catwalk for the first time. Most of them say that they are both nervous and excited about the whole event. I know however that they will have a most wonderful time. At the end of the show the models are usually enlivened, excited, overwhelmed and wishing that they could do it all again.

“This year’s models range in age from 27 years-old to 53 and come from Bedfordshire, Gloucestershire, Hampshire, London, Milton Keynes, Oxfordshire and Surrey.

“We are delighted once again to be showing Apricot, Simply Be and London Ethnic on the catwalk this year. Donations for our goody bags have been received from Barry M, Just Bee drinks and Sainsbury’s. And Philip Treacy has very kindly once again donated a hat to be auctioned, in memory of his late friend Isabella Blow. Thanks to all.”

TO BOLDLY GO

Ovacome member Becky Parsons (right) sums up the feelings of the group of Tea with Ovacome models, feeling a mixture of terror and excitement about the prospect of taking to the catwalk at this year’s event.

Becky says that since being diagnosed with stage 1c ovarian cancer in April 2015, aged 48, she has become determined to live boldly.

“l was fortunate enough to be in the minority of women to catch it at an early stage,” says Becky. “Taking part in the fashion show is so far beyond my comfort zone, but I feel that I have been given the opportunity, denied to many women diagnosed at a later stage, to raise awareness and funds.”

Like many women Becky’s ovarian cancer took a while to be diagnosed, despite visiting the doctor over the previous year with various symptoms including a bladder infection, light spotting, bloating, backache, an abdominal lump, tiredness and passing urine more frequently.

It was only when an ovarian cyst grew to 15cm and Becky said she looked pregnant that a scan revealed there could be a serious problem. A month later she had surgery when it was discovered she had endometrioid ovarian and endometrial cancer.

After the surgery and six rounds of chemotherapy Becky needed treatment for primary kidney cancer. Fortunately, she says, she has been in remission from all cancer for the past year.
During spring and summer, at Ovacome’s Members’ Day and the Tea with Ovacome fundraising event, you will probably come across fellow Ovacome members wearing this beautiful sleeveless black dress with teal and baby pink flowers on it.

That is no coincidence. This chiffon tie back dress is the latest design from fashion retailer Apricot to raise money for Ovacome. Be on trend and support Ovacome by purchasing the £29 dress, which is available in sizes 8 to 16 in one of the fashion retailer’s 10 stores in London’s Westfield White City, Stratford, Bath, Bluewater, Cardiff, Crawley, Croydon, Derby, Lakeside and Milton Keynes or online at www.apricotonline.co.uk

All of the profits from its sales will be donated to the charity and with florals remaining a key fashion trend for spring/summer 2017, Apricot has high hopes for big sales for its 2017 Ovacome dress.

“Following the success of last year’s dress we decided to keep the print floral for 2017,” says Apricot’s managing director Sophia Ciampa. “We love a statement bloom”, she says. “The print has been developed on a floaty chiffon fabric and placed on a shape that flatters all sizes, as the tie detail accentuates the waist. Every wardrobe needs a black dress and this one has added flower power!”

Almost 500 clinical students benefited last year from a scheme in which women who have been treated for ovarian cancer tell them their story with the hope that it will stay with them as a reminder of the symptoms when they qualify.

Ovacome’s Survivors Teaching Students talks, launched with a donation by the Clark family (see below) to promote early diagnosis, have gone down so well that course leaders are including its volunteers in other areas of student teaching.

As well as STS being embraced by a dozen UK medical and nursing schools, Oxford University medical school, for example, has involved the volunteers in formulating student exam questions, using their real-life examples of late diagnosis. City University in London has asked them to help with student recruitment on its radiotherapy, radiography and nursing courses. And the volunteers have approached their local and work communities offering awareness talks, with a special event being put on for the City of London Police.

One of the presenters Jane Chilton from Rustington in West Sussex has found the experience worthwhile.

“It is difficult talking about unpleasant events in your life, but I have done it three times now and it has actually helped me to come to terms with what happened and move on,” she says.

“I did get a reaction from the students when I talked about some of the poor care I received, which was affirming and made me think ‘well, they won’t do that’.”

It began with a postcard of a penguin. Before she died of ovarian cancer, Lisa Clark, a young doctor, had left her parents Roger and Lynette money to see the world, something her illness had stopped her from doing. Her father Roger was determined to go to Antarctica to photograph the same penguin pictured on the postcard he had received from Lisa all these years before. Last year, he fulfilled that ambition (pictured). The Clarks’ generous donation, in memory of Lisa, has helped get Ovacome’s Survivors Teaching Students programme off the ground (see above).
Olaparib, the tailored therapy known to extend remission of women who are being treated for ovarian cancer and have the BRCA gene mutation, has been approved for use in Scotland.

Ovacome welcomes the Scottish Medicines Consortium announcement that the parp inhibitor will be offered routinely in Scotland to BRCA 1 or 2 positive women, who relapse with platinum sensitive high grade serous cancer after two or more platinum chemotherapy treatments.

But Ovacome’s chief executive Louise Bayne would like to see further progress in accessibility to the drug south of the border, where women in England and Wales can only access olaparib for ovarian cancer after three or more platinum chemotherapy treatments.

“This is great news for the development of personalised treatments for women with advanced ovarian cancer,” says Louise. “However, a number of patients who would benefit from olaparib still can’t access the drug. We want all women to have access to the most advanced treatments medicine has to offer in what can be a difficult to treat condition.”

Also, urges Louise, for women to take advantage of this decision they should ensure that they ask for a BRCA test when they are diagnosed in Scotland, or at least if the cancer returns. “It is even more important now that NHS Scotland must continue to ensure that all ovarian cancer patients are offered a BRCA test at diagnosis so they can be treated with the best drugs available,” says Louise.

Screening for a condition linked to ovarian cancer

NICE recommends the wider use of tests to detect a genetic condition which has been linked to an increase chance of developing ovarian cancer, as well as disease of the bowel, womb and stomach.

In draft guidance published for consultation, NICE has recommended that everyone who is diagnosed with colorectal cancer should be tested for an inherited genetic condition called Lynch Syndrome.

Testing for the condition helps to identify whether the patient’s family may also be at increased risk of cancer, meaning they could be monitored more closely if needed.

High impact awareness

Ovacome members Cher Oddy (right) and Claire McIlvenna are featuring in high impact cancer awareness campaigns this spring.

Cher from Faversham in Kent is taking part in a PR campaign celebrating the quality of NHS care that incurable patients receive, including access to much needed life-extending medicines providing quality of life.

The initiative is being funded by Roche, which is working with Ovacome and a number of other cancer charities, to say thank you to those who strive to improve terminal cancer care, but will ask what the future holds for patients diagnosed tomorrow and beyond.

Cher, who has been told her ovarian cancer is now incurable (see page 12), stars in the heart-warming film being launched as part of the campaign, dancing to a very special version of ‘I’ve had the time of my life’.

Claire, from Wolverhampton, is taking part in the Be Clear on Cancer awareness campaign which is running from February 9 to March 31 in the East and West Midlands.

The regional pilot is concentrating on awareness for abdominal symptoms, that have lasted for three weeks or more as potential signs of cancer. As well as ovarian cancer, the primary cancers this campaign is focusing on includes bowel, pancreatic, bladder; Non-Hodgkin lymphoma, kidney and womb.

Raising awareness of symptoms and encouraging earlier visits to GPs is the aim of the campaign, run by Public Health England in partnership with the Department of Health and NHS England, and supported by Cancer Research UK.
Dr Ros Glasspool: trials are not a last resort.

Some women might avoid going on a trial in case they are put in the placebo arm.

RG: “A woman would never be denied treatment by being on a trial. Often the placebo is given in addition to standard treatment so participants would not be missing any treatment by being on the trial, but they might not receive the additional experimental treatment.

“If there is an arm with placebo alone this is because the standard management is not to have any treatment in this situation. An example would be when we test new maintenance treatments after chemotherapy where women would usually be being followed up but not receiving any treatment.

“Placebo controlled trials are important because a new treatment may not be effective and will have side effects so it is vital that we test each one in as fair a way as possible to see if they really do help.

“Placebo is a way of stopping both women and their doctors from knowing if they are on standard or experimental treatment. Although they wouldn’t mean to, doctors and patients could inadvertently affect the results of a trial if they knew whether they were on the experimental treatment or not.”

How does randomisation work?

RG: “Randomisation ensures that women are allocated evenly to the different arms of the trials so there is no bias in the results. There could be many reasons why some women will do better or worse, for example how advanced their tumour is or other medical conditions and if these aren’t evenly balanced then any apparent benefit seen in an arm of a trial might not be due to the treatment at all.”

What quality of treatment safeguards are in place?

RG: “Trials are carefully designed and reviewed by panels of specialists and patient representatives to ensure that a trial offers appropriate treatment whatever arm a woman draws.

“They also review whether the question that they are addressing is important and whether the trial will be able to answer the question. The trial is then reviewed by an ethics committee: an independent panel of experts and lay representatives. Its responsibility is to protect the safety and rights of any research subject. It must give permission before a trial can start and it can request changes to the design.”

With Ovacome planning to launch an online clinical trials finder search tool for its members this year, we ask Dr Ros Glasspool when women with ovarian cancer might want to consider logging on.

Should a clinical trial be considered as a last resort?

RG: “It should not be a last resort, but should always be carefully considered within the context of a woman’s current condition. There are important questions that can be addressed by trials at all stages from reducing risk, improving diagnosis, initial treatment, treatment for relapsed disease and supportive care.

“Women should always feel comfortable asking about clinical trials that might be suitable for them. If a trial is not available at their local centre they may be able to travel to another centre for treatment. Some people do see trials as a last resort, but there may be trials for people at all stages.

“Ovacome’s new online search tool will help both doctors and women find trials that might be suitable for them and so improve access to trials for all women who would like to participate.”

Continued on page 10
What safeguards are in place?
RG: “Patients are looked after by doctors with experience in trials and the treatments being studied. Their side effects and how their cancer is responding are regularly reviewed. If a patient has a serious side effect or any time they need to be admitted to hospital, this is reported to the pharmacovigilance team within 24 hours and reviewed by the doctor in charge of the trial. “Anything unexpected is investigated thoroughly and reported to the UK authority, the Medicines and Healthcare products Regulatory Agency (MHRA). This ensures that any new safety concerns are picked up quickly.

“The outcomes and side effects experienced by people on trials are regularly reviewed by another independent committee known as the independent data monitoring committee to make sure that there are no safety concerns and that it is reasonable to continue the study. It can stop a trial if there is concern that people in one arm of the study are doing significantly less well or they are experiencing too much in the way of side effects. The ethics committee also receives regular updates.”

How easy is it to come off a trial?
RG: “A woman can leave a trial at any point and she does not have to give a reason. Her doctor may recommend some visits and tests to monitor and treat any side effects that are still going on if concerned about her safety, but women don’t have to accept these.

“Equally, some women will decide to stop treatment on a trial but be happy to be followed up to see how they get on after they stop. It can be helpful to know why a person wants to stop being on a trial to help improve the way a trial is conducted but this is not obligatory.”

How are phases one, two, three and four different?
RG: “New treatments are investigated in phases and the information learnt from the first phase is used to decide on the next phase of trials. In phase I trials it may be the first time a new treatment or novel combination of drugs has been given to humans. These trials investigate safety of a new treatment and work out the dose and schedule that should be used in future trials.

“Phase II studies start to explore whether a new treatment has a benefit at the same time as continuing to gain information about the safety. Phase III trials then go on to investigate whether treatments that were promising in a phase II trial are better than standard treatment. Phase III trials generally need a large number of people to answer that question.”

How are the practicalities different when being treated on a trial?
RG: “Being on a trial does involve some commitment. Drug trials often have long information sheets that can be hard to read. It is important that people ask questions and make sure they understand everything and know what is involved in a trial. There may be additional investigations and visits.”

What are the benefits of being on a trial?
RG: “If you are on a trial you will be monitored very closely. You may have the opportunity to receive a new treatment that you would not otherwise be able to try but there is no guarantee that the treatment is effective or better than standard treatments. Also you will be contributing to the understanding of your type of cancer and helping to develop new treatments that might benefit other people in the future.

“There are often extra visits and investigations but women often find it reassuring to have the extra monitoring and regular contact with the trial team including the research nurses who give a lot of support. They often feel very positive about the contribution they are making to the care of women in the future.”

How important is it that women take part in trials?
RG: “It is vital to furthering our understanding of ovarian cancer and finding new treatments that women volunteer to go into trials, but no woman should feel obliged to go onto a trial. It must be right for her.

“Participating in clinical trials is also important for doctors. It generally helps to improve the way that all patients are looked after whether they are in a trial or not. It helps to keep your knowledge at the forefront of advances.”

What advice would you give to women considering entering a trial?
RG: “Ask questions and make sure you understand what is involved and if you are happy with that then I would encourage women to participate. Remember you can always come out of a trial if you want to.”

• Dr Ros Glasspool is a consultant at the Beatson West of Scotland Cancer Centre.
I was referred to geneticist, Professor Diana Eccles in my 30s, due to a family history of ovarian and breast cancer including my mum, aunt, cousin and grandmother - with the suggestion of being tested for the BRCA1 gene mutation.

I tested positive, as did my cousin who had prophylactic surgery to reduce her risk of cancer, but unfortunately she developed ovarian cancer on the peritoneum and died very soon after aged 51. This made me wary of surgery and, as such, I decided against it.

In June 2015, with no symptoms, a routine CA125 blood test at my vigilant GP’s office was very high and I was later diagnosed with stage 3c ovarian cancer – and subsequently had surgery and treatment (paclitaxel and carboplatin) until December 2015.

After surgery, in August 2015, I contacted Care Oncology Clinic (COC) in London. I had read about their ‘repurposing’ drug initiative in the Daily Telegraph, which involves Metformin, statins and two antibiotics.

This is very affordable at about £1,000 the first year with follow-ups pretty much at my own discretion. COC advised me to start immediately with its protocol, alongside conventional chemo.

I am now aged 61 and have had no evidence of disease for just over a year. Folk say I look very well, better than ever, (go figure). I have a small surgical hernia, osteoarthritis in my back and a touch of neuropathy in my left hand. All completely bearable after all, as I know you must be aware, I have been through.

My GP, oncologist and geneticist are amazing and are supportive of my visits to COC. Let’s hope its protocol continues to work for as long as possible or better still, forever! I already know my insurance won’t cover Avastin or PARP inhibitors at £40,000 a year.

That’s my story. I wish you all the best of everything.

Sherry Millan, Alderney, Channel Islands.

Our online community

In August 2015, at the age of 64, I went to see my GP about a minor complaint and came home in a state of shock. He had found a large lump in my tummy and suspected ovarian or bowel cancer.

In October 2015 I had a total abdominal hysterectomy then six cycles of carboplatin and taxol chemotherapy, which ended in April 2016.

After my third cycle of chemo in February 2016, I developed numbness in my feet and fingertips, and about this time, I began to wish I could speak to other ladies with ovarian cancer. It was then that I discovered that Ovacome was part of an online forum under the umbrella of HealthUnlocked, so I signed up to join.

Belonging to such a supportive group of people, who have inspired with their accounts of living with ovarian cancer for many years, has been most encouraging. I also found answers to queries I had and received helpful tips for dealing with the neuropathy in my feet, and subsequently was able to contribute hints from my own experience to help others.

Members can rant and moan when things are tough, and equally share milestones of achievement such as finishing chemo or being told they are free of disease. The other week a few people in the south east met for brunch together and had an enjoyable time.

Being in touch with other ladies in a similar situation reduces the sense of isolation the disease can bring and means it is possible to share things that family and friends simply can’t understand. Practical advice ranges from packing for hospital when having surgery, to coping with chemo side effects and many other related topics.

Newcomers to the site can be reassured that the treatment is not as awful as they expect and most importantly that they are not alone, but part of a large group of ladies who have had similar experiences and lived to tell the tale.

If you have access to the internet and would like to be in contact with other ladies coping with ovarian cancer, do come and join us. I can promise you won’t be disappointed!

Barbara Greenall, Forest Hill, south-east London.
I was diagnosed with stage 3 ovarian cancer in August 2011 aged 49. I had a recurrence two years later and have been told that my disease is now incurable. We treat the symptoms, not the disease.

And I had lots of reactions to the second-line carboplatin and gemcitabine, which niggled my veins during five months of treatment, so that I had to be fitted with a PICC line (a peripherally inserted central catheter), which I had at my youngest daughter’s wedding party with a tattoo sleeve: much more me than the covers that were available.

But having ovarian cancer has opened so many doors. I have taken part in television, radio and magazine interviews and photoshoots for brochures about cancer. I’ve been invited to Westminster to lobby MPs for better symptoms awareness training for GPs.

Last year I even strutted my stuff down the catwalk for Tea With Ovacome where I was totally out of my comfort zone, but enjoyed every minute, making new friends.

With these ladies, Facebook ovarian cancer pages and the Macmillan incurable cancer community I have a fantastic support network. I can say anything to fellow cancer warriors in these groups without having to explain how I feel. I can be open and honest in a way I can’t be with family and close friends, as I can’t bear to see them upset.

I can talk about what to do with my clothes when I’m no longer here, or what music to have at my cremation - I currently have 14 songs so I need to whittle these down. Also should I have a party before my departure rather than a wake when I’ve gone?

Anyway, this is not the time for these thoughts. I intend to be around for quite a while yet, as I have many activities to complete on my ‘50 things to do list’. The main one is to renew my passport to visit countries I wish to see. Another, which I hope to have carried out by the time this letter is published, is to have another tattoo: a lotus flower on my wrist signifying my rebirth since diagnosis.

Cher Oddy, Faversham, Kent.

May 2007 arrived and I was well into my chemotherapy, taxol and carboplatin. I had no hair but a super wig. I was shattered and bloated with steroids but I had a new outfit to wear and the doctors gave me a week off to be able to attend the wedding. Amazing. We had a truly memorable day and I even had a few dances.

Almost 10 years later and my daughter and husband now have two lovely daughters of their own and my other daughters are married with wonderful children too. I enjoy every moment with them all.

There is life after cancer even with a poor prognosis. I cannot thank the doctors and nurses enough at Glasgow’s The Royal Infirmary and The Beatson West of Scotland Cancer Centre. Without their expertise and the support of my family and friends I might have missed so much.

To anyone starting treatment keep strong.

Kate Stevens, Glasgow.
Promoting awareness
To Jigna Patel and all the wonderful women who put on regular events for their community. They organised a gathering for the elderly people in their Hindu community to increase awareness of dementia and ovarian cancer. The ladies and gentlemen who attended were incredibly generous in their donations; they split the proceeds and raised an amazing £1,626 to support our work.

Raffling a cake
Chilie Davies for creating a most fabulous novelty Christmas cake to raffle at the Pill Community Café in Bristol. The lovely customers were wonderfully kind and all the ticket sales raised a fabulous £75.

Lots of marathons
To Craig McMurrough who took to the streets of New York and Amsterdam to run their marathons and raised a brilliant £1,080.30. Craig will also be running the London Marathon in April, as well as the Great North Run.

Avon sale
To Ruth Pearson who arranged a most fantastic evening with an Avon Sale, Pool K/O and a fashion show. She also received a donation from F2F (face to face) nail and beauty parlour and in total raised a magnificent £210.90.

Bake sale
Jane O’Donnell and her daughter Megan and friend Liz worked hard and created such beautiful cakes to sell at work. They really looked so lovely. All their colleagues were very generous and bought everything and raised a superb £115.06.

Zip line
To the very brave Clair Birks and her husband who shot down the longest zip line in the world, in Wales, reaching speeds up to 100mph and raised a fantastic £377.26.

Drastic hair cut
Rena Nelson decided to arrange an evening of bingo, a raffle and cake sale, with the great night of fun also including Rena getting a very drastic hair cut to raise money for Ovacome on behalf of her good friend Jill Luce. Everyone involved raised a stunning £3,710.44. (See page 14).

Portsmouth
Jayne Hooper donned her running shoes and took to the streets of Portsmouth and its beautiful surrounding countryside and ran the Great South Run. Jayne raised a fantastic £626.45.

Total team event
To Character Group in Oldham, and Rebecca Scoltock who arranged yet another truly memorable event in memory of their dear friend Lynn. Many of the men got waxed and Jacqueline Haigh got her head shaved! They plan to have an event every year on Lynn’s birthday. Their fantastic evening raised a truly wonderful £2,076.88.

5K
To Barbara de Abreu, Cherryl Cooper, Karen Alexander, Pasquale Lalongo, Maurina Jocintho, Roseanna Jocintho and Angelo Martino who all pulled on their running shoes for the 5K course of the Belfius Marathon and Half Marathon in Belgium and raised a wonderful £910.56 which included a generous match funding from Cherryl’s work, Grant Thornton LLP.

Surprise!
Lynn Shipley arranged a wonderful surprise 60th birthday party for her husband. It all went to plan and he did not suspect a thing!

Costume run
To Rebecca Milling’s husband Paul and son Oli who took to London’s Victoria Park, dressed as Father Christmas, for the annual Santa Run which looked such good fun. Between them they raised a really fabulous £428.75.

Everyone
To everyone that has raised vital funds for Ovacome, sorry we cannot mention all events.
Some people will go to any length to help others through a cancer diagnosis and in Ovacome member Jill Luce’s case, a friend had a full 12 inches lopped off her hair in a netball club bingo night to raise money for the charity.

Jill’s friend Rena Nelson, a team mate in the St Lawrence Netball Club, had hoped that the hair raising stint would bring in £1,500 for the charity and she was delighted that the final figure was more than double that at £3,730.44. Also, Rena was able to donate her cherished hair to a trust which makes wigs for sick children.

Jill, who has been a member of the Jersey netball club for the past 20 years and was originally diagnosed with ovarian cancer in March 2012, was overwhelmed.

“The first I knew that Rena was plotting a fundraising event, was her enquiring as to which would be my preferred charity, and without hesitation I replied Ovacome,” says Jill, who has found our online chat forum particularly useful. “To then find out she had the backing of the entire netball club, I was incredibly humbled and very emotional. Their support both on and off court help me in more ways than they could ever know, and for that I will be eternally grateful.”

Last autumn Jill had to take a break from netball for five weeks of radiotherapy to treat a third recurrence, but she is now back to playing.

Leaving a gift in your will

By leaving a gift in your will you can help us change women’s lives. Every single pound has the power to make a difference and help us transform stories of loss into stories of survival. Please consider supporting us in this very special way and help our work continue.

Tax rules may mean that if you leave at least 10% of your estate to charity, the inheritance tax rate on the rest of your estate may reduce from 40% to 36%.

Contact Lee Priestly on 020 7299 6651 or email her at l.priestly@ovacome.org.uk

Walking in her daughter’s shoes

Lilian Marris has been leaving footprints in memory of her daughter Caroline who she lost to ovarian cancer, by organising a Humber Bridge walk in her memory.

The event was organised for the same time as the Teal and Toe Walk, which Caroline started five years ago, in Seattle where she lived, with over 300 walkers.

Lilian raised over £700 for Ovacome and this was followed by generous donations from friends. The congregation at Lilian’s local church donated £600 and she raised £150 from her weekly coffee morning. The Kirton in Lindsey Table Tennis Club in Lincolnshire that Lilian and her husband attend also wanted to show its support and donated £250.

Lilian has been fundraising for Ovacome for seven years from selling our pins, donating instead of receiving gifts for her wedding anniversary, holding regular coffee mornings and organising other fundraising walks over the Humber Bridge with friends.

Lilian’s daughter Caroline had helped on the American Survivors Teaching Students initiative and gave various nursing and female group talks in the hope that her story would leave an imprint in their minds as they witnessed the symptoms.
To celebrate its 20th anniversary Ovacome has come up with the ‘Because you are special to me’ keepsakes. Made from rosewood and each retailing at £14.95, they are designed for Ovacome members to give to each other as tokens of support and friendship, as well as for gifts to raise awareness.

They are being launched for awareness month with Hickory Dickory Designs this March - when they will be perfect for Mother’s Day. But they will be sold throughout the year as beautiful items to keep forever.

The keyrings and mini plaques arrive in a beige, linen pouch, tagged with the ‘Because you are special to me’ message. And a donation is being made to the charity by Hickory Dickory Designs for every purchase.
WE ARE HERE TO HELP YOU

Speak to our specialist team
We run a support line five days a week from 10am to 5pm. You can speak to us about signs, symptoms, relapsed ovarian cancer, treatment options, BRCA testing and more. You can also email us any time on support@ovacome.org.uk
Call the Freephone number 0800 008 7054.

Find a local support group
There are over 40 regional support groups which provide an opportunity to meet other people who are in similar situations and to talk about your experiences in a safe space. You might learn from those a little ahead of you in their journey and follow some of their strategies for coping.
For a full list of support groups visit www.ovacome.org.uk

Support for younger women
Ovacome runs a support group for younger women diagnosed with ovarian cancer. This group meets on the first Wednesday of every month at Maggie’s in Hammersmith.
We also have a guide for younger women that covers concerns and issues which younger women with ovarian cancer face.
For more information about the support group or to order our guide please call 0800 008 7054.

Looking for information on ovarian cancer
We offer a range of fact sheets which provide clear, straightforward information on ovarian cancer.
For a full list of titles and to order your copies please visit www.ovacome.org.uk or contact us on 0800 008 7054.

Online community
We have an online community of over 4,000 members who have been affected by ovarian cancer. The forum is clear and simple to use and allows members to communicate at any time and discuss a number of concerns, issues and more. You can visit the forum here: healthunlocked.com/ovacome.

One member says: “I find the MyOvacome forum useful for sharing information and giving/receiving support.”

Members’ Day
Our annual members’ day event will be held on Saturday 4 March 2017, where we will be joined by world class health professionals who will present information on the latest research and progress on ovarian cancer. It also provides an opportunity to meet the team and others affected by ovarian cancer.
Please find further details on page 4.
To book your place call 0800 008 7054.

Other useful organisations:
Penny Brohn Cancer Care offers a range of services, including residential and day courses, which are free of charge to adults with a cancer diagnosis and their supporters. They aim to show people how to live well with cancer and take back control of their health and wellbeing, before, during and after treatment.
- www.pennybrohncancercare.org
- 0845 123 2310

British Association for Counselling and Psychotherapy
Visit www.itsgoodtotalk.org.uk to find information about counselling and details of therapists in your area.
- 01455 883 300

Relationship support
Relate offers counselling, support and information for all relationships, with centres across the UK. Visit www.relate.org.uk/about-us for more information and to book a session.