

News from Target Ovarian Cancer

On Target

January 2017



**Pathfinder
study**

**Ovarian Cancer
Awareness
Month 2017**

**Our new
nurse-led
support line**



Welcome



We launched our latest Pathfinder study in parliament towards the end of 2016 in a rush of media attention and conversations both on- and offline. In this issue you can find out more about this unique and groundbreaking research.

We found that, while awareness of the symptoms of ovarian cancer has risen significantly among women in the UK since Target Ovarian Cancer was established, the increase is beginning to level off and still just one in five is able to name bloating as a symptom. Together, we're working to change this so that we live in a world where every woman can name the symptoms of ovarian cancer, and it's vital that we keep up the momentum.

Our next big opportunity to spread the word is Ovarian Cancer Awareness Month in March. Plans are underway to make it the biggest year yet, and you can find out how to get involved on p10. Please join us!

With best wishes for the new year,

Annwen Jones
Chief Executive

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Target Ovarian Cancer
2 Angel Gate, London, EC1V 2PT



020 7923 5470



info@targetovariancancer.org.uk



targetovariancancer.org.uk



TargetOvarianCancer



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Cover image: Target Ovarian Cancer Chair Joanna Barker (left) and Chief Executive Annwen Jones meet with Community Health and Care Minister David Mowat at the Pathfinder 2016 launch.

News

Launch of genetic testing and hereditary ovarian cancer guide

Since we launched our new information guide, *Genetic testing and hereditary ovarian cancer* in August 2016, over 2,000 copies have been read by women across the UK.

The guide, which can be ordered in print or downloaded from our website, offers advice on everything from genetic testing to the emotional implications of the different results of a test.

Researchers estimate that 15–20 per cent of ovarian cancer diagnoses are caused by a genetic mutation such as those in the BRCA genes. It is vital that women who have already been diagnosed – or those who might be at risk – have access to expert information and support.

To get your copy, visit targetovariancancer.org.uk/genetics



New year, new dates for your diary

Being Together days are a great opportunity to meet other women living with ovarian cancer, and 90 per cent of women say they feel less isolated after attending.

Join us in **Wrexham on 4 April** or in **Sheffield on 4 May**.

For details, visit targetovariancancer.org.uk/beingtogether or call **020 7923 5475**

We are award-winning!

We're thrilled to announce that *A Younger woman's guide to ovarian cancer* has won a British Medical Association (BMA) Patient Information Award.

Every year over 1,000 women under the age of 50 are diagnosed with ovarian cancer. On top of dealing with the emotions of a cancer diagnosis and the physical effects of treatment, younger women often face challenges including the loss of fertility and facing an early menopause. The guide, produced in partnership with three other charities, provides crucial information and signposting to help women through a diagnosis, and we're honoured that it has been recognised by this year's BMA panel.

To order or download any of our information guides, visit targetovariancancer.org.uk/guides or call **020 7923 5475**

News

Can enough women access clinical trials?

Pathfinder 2016 revealed that just one in four women with ovarian cancer has taken part in a clinical trial at some point, and that over half of women who are not currently on a trial say they want to join one. This leaves very few women able to access the latest drugs and therapies.

In December, Target Ovarian Cancer presented a new analysis of participation in ovarian cancer clinical trials to the Gynaecological Cancer Clinical Studies Group at the National Cancer Research Institute (NCRI).

We found that, while participation in clinical trials has improved across the UK in the past year, there is still a lot of variation in access depending on what part of the country a woman lives in – with up to six times more trials open in the best-performing regions than others.

The team at the NCRI will use the findings to inform their work to ensure more women have access to clinical trials across the UK.

To find out more, visit targetovariancancer.org.uk/NCRIclinicaltrials



Wales Cancer Patient Voices

Honouring a commitment made to Annie Mulholland, who died of ovarian cancer in 2016, Target Ovarian Cancer has joined forces with charities Tenovus and Breast Cancer Now to help continue the Cancer Patient Voices work started by Annie. Her work centred on giving people with a cancer diagnosis a voice in cancer treatment, research and policy.

Last October we helped to organise a meeting at the Welsh Assembly for patients to decide their priorities for campaigning in Wales. In January, Wales Cancer Patient Voices will hold an event with Welsh Assembly Members to share their priorities and ask how politicians plan to work to improve cancer services in Wales.

One in four women with ovarian cancer has taken part in a clinical trial.

Campaigns corner

Top GPs meet

Our GP Advisory Board, chaired by Professor Nigel Sparrow OBE, met in November to discuss some of the next steps in diagnosing women earlier.

The GPs discussed Pathfinder 2016, the current review of National Institute for Health and Care Excellence (NICE) guidelines covering the diagnosis of ovarian cancer, and progress on England's new cancer strategy.

The group agreed that the challenges GPs can face in ordering ovarian cancer diagnostic tests (CA125 and ultrasound) meant this was something that they would focus on in the coming year.

MPs discuss prevention and early diagnosis

The All-Party Parliamentary Group (APPG) on ovarian cancer, chaired by Sharon Hodgson MP, recently met at the Houses of Parliament to discuss issues of prevention and early diagnosis of ovarian cancer.

The November meeting included talks from Dr Marc Tischkowitz, who discussed his research into genetic testing and Dr Victoria Barber, who works with Target

Autumn action in Scotland

In September Target Ovarian Cancer went to the Detect Cancer Early Conference in Glasgow.

Policy makers, health professionals and patient organisations met to discuss progress to date in improving early diagnosis of all cancers in Scotland. We shared new ideas and looked at future objectives. Scotland is significant because it has reformed its diagnostic pathway for ovarian cancer so that the CA125 blood test and ultrasound are carried out at the same time, which should see women diagnosed faster.

Ovarian Cancer on GP education. The meeting also included an update on the Be Clear on Cancer ovarian cancer awareness campaign.

If you would like to find out more about the meeting, or are interested in attending future meetings, please contact APPG@targetovariancancer.org.uk or call 020 7923 5470

Scotland is significant because it has reformed its diagnostic pathway. This should see women diagnosed faster.



Target on

Pathfinder 2016

Pathfinder 2016 builds a picture of the experiences of people living and working with ovarian cancer in the UK. Here are some of the key findings of our groundbreaking study.

Awareness of symptoms

Women need to know the symptoms of ovarian cancer so they can go to their GP at the earliest opportunity. Awareness has risen since the first Pathfinder in 2009, with one in five UK women now able to name bloating as one of the main symptoms of ovarian cancer. This shows that the work we have all put into raising awareness is paying off and more women now know the symptoms to look out for. However, it also shows how much

remains to be done and Pathfinder 2016 calls for governments in each of the four nations to fund national awareness campaigns.

Diagnosis

GPs are vital in ensuring more women are diagnosed sooner. Pathfinder 2016 shows that GP knowledge of ovarian cancer is increasing, but 44 per cent of GPs continue to believe that symptoms only occur in late stage disease and 41 per cent of women are having to visit their GP three times or more before being referred for diagnostic tests. GPs' growing knowledge and the gradual debunking of myths around the diagnosis of ovarian cancer show the impact of our work to train GPs but also the need to step this up so that every GP knows the symptoms to look out for.

Genetics

Among women in the general population, just one quarter think that genetics might be a factor in developing ovarian cancer and just under half of women with ovarian cancer (44 per cent) are aware there might be a genetic link.

Women with ovarian cancer are very clear on the need for support in deciding whether to proceed with genetic testing, with 86 per cent saying women should be offered genetic counselling to help prepare them. Research by Dr Marc Tischowitz, funded by Target Ovarian Cancer, developed a model to ensure all women with ovarian cancer are offered counselling by genetic services prior to being tested and this is now being rolled out across the UK.

Support

Clinical nurse specialists (CNSs) provide women with ovarian cancer with the specialist care and support they need. Pathfinder 2016 shows that CNSs are becoming increasingly stretched. Less than half of them (46 per cent) believe that their cancer unit has enough nurses to care for all the women being treated there and just 63 per cent say they are able to meet all of women's medical needs such as symptom control.

Many women with ovarian cancer report going without the support they need, both in managing symptoms and treatment side effects, but also with managing wider issues such as body image and mental wellbeing. 80 per cent of women say they have experienced mental ill health as a result of their diagnosis.

Recurrence

Pathfinder 2016 found that despite half of women (51 per cent) needing support coping with the fear that their cancer will come back, two thirds of nurses (63 per cent) say they don't have time to explain the symptoms of recurrent ovarian cancer to women. It also showed that many women with recurrent ovarian cancer are not receiving the same level of support as when first diagnosed.

Guidelines for the treatment of recurrent ovarian cancer already exist in Scotland, and Pathfinder 2016 calls for National Institute for Health and Care Excellence (NICE) guidelines for women with recurrent ovarian cancer to cover the rest of the UK to ensure all women with ovarian cancer receive the highest possible standard of treatment and care at every stage.

"I am involved in Pathfinder 2016 because I want to make sure that every woman receives the same care and support as me. Pathfinder gives us the evidence and we will use it to show parliamentarians, healthcare bodies and the public what needs to be done."



Christine Mitchell was diagnosed with ovarian cancer in 2013 and was on the Pathfinder Advisory Panel.

Securing change

We launched the UK wide report in parliament, and the Minister for Community Health and Care has committed to working with Target Ovarian Cancer to take the recommendations set out in Pathfinder 2016 forward.

In 2017 we will produce separate reports for each of the four nations and plan launch events in Northern Ireland, Scotland and Wales.

To read Pathfinder 2016 and for more information visit targetovariancancer.org.uk/Pathfinder2016



Supporting you

Need to talk? We're here for you

We know that a diagnosis of ovarian cancer can be difficult, with 35 per cent of women saying they have needed support with feelings of isolation. The number of calls we receive has been climbing steadily and your donations have enabled us to launch a new nurse-led support line, providing vital emotional and practical support to women living with ovarian cancer. Having someone to talk to can really help...

Whether you or someone close to you has been diagnosed with ovarian cancer or is concerned about the symptoms, our confidential nurse-led advice, information and signposting service can offer emotional support or help answer your questions.

The support line is managed by our Nurse Adviser, Jane Loughnane, a registered nurse for 30 years. Jane has spent her career focusing on cancer nursing and chemotherapy, and has a degree in cancer care.

Jane says: "We receive a lot of calls and emails from women concerned about ovarian cancer symptoms, their diagnosis, treatment or the emotional impact of completing treatment. My role as Nurse Adviser – and the launch of the Target Ovarian Cancer support line – will fill this clear, unmet need and support women to live well with ovarian cancer.



"We know that this essential service is greatly needed when 51 per cent of women with ovarian cancer say they have needed support coping with the fear of recurrence, and 35 per cent of women have needed support to deal with feelings of isolation. By being available on the phone I also hope to provide vital information and show women ways to connect with others online and in person."

Target Ovarian Cancer's nurse-led support line will support women to live well with ovarian cancer.

**Call us on
020 7923 5475**

How does the support line work?

Have you got a question about ovarian cancer? Are you worried about an upcoming appointment and need support? Whatever your concern, you can get in touch with us.

Call 020 7923 5475, Monday-Friday between 9am-5.30pm and you'll either be put straight through to our nurse adviser Jane or we will arrange for a call back at a time that suits you.

You can also email Jane directly at support@targetovariancancer.org.uk or send your queries to our Ask the Experts service at targetovariancancer.org.uk/experts

What is the Ask the Experts service?

Working alongside Jane, we have a panel of clinical advisers – ranging from medical oncologists and surgeons, to geneticists, clinical nurse specialists and GPs. They generously volunteer their time to help provide accurate, evidence-based information to support more women with ovarian cancer.

Since the service launched just over a year ago, our experts have responded to hundreds of queries - answering questions about anything from genetic testing, to diet and travel insurance.

To have your question answered, or to browse questions that have previously been answered, visit targetovariancancer.org.uk/experts

A personal perspective...

Since starting the nurse-led support line at Target Ovarian Cancer, Jane has spoken to many women affected by ovarian cancer – women like Susan...

"I rang Target Ovarian Cancer because I was being assessed for ovarian cancer. I was going through the tests and I needed more information.

"You were extremely helpful and kind, explained things well and emailed me lots of information too. Thankfully I got my ultrasound results today and nothing was found. I thought of your help and just rang Target Ovarian Cancer and made a donation. I mentioned how much you helped me. It is good to know that you and your charity are here to help women with their concerns about ovarian cancer. Thank you."

"It is good to know that your charity is here to help women with concerns about ovarian cancer."



Get involved

Ovarian Cancer Awareness Month

Do something magnificent this March – join others like Kath for Ovarian Cancer Awareness Month...



When I was diagnosed with ovarian cancer, it came as a shock because I hadn't heard of the disease before – and didn't know the symptoms.

"I discovered Target Ovarian Cancer and learned about the charity's work raising awareness. I wanted to help save lives, so last March with help from family and friends I held an afternoon tea for Ovarian Cancer Awareness Month.

"Target Ovarian Cancer staff were so helpful, providing ideas to get me started and free materials – including symptoms leaflets for our 40 guests and balloons which we used all over the house!

"I wanted to help save lives, so I held a fundraising event for Ovarian Cancer Awareness Month"



"We baked scones, cakes and some savoury snacks as well as holding a raffle. There was lots of laughter – and as people left they even said they were looking forward to catching up next year. Donations for the treats and raffle tickets raised over £600. It turns out we raised enough to let over 1,400 people know about the symptoms *and* fund a day of medical research into new treatments."

Being diagnosed at the earliest stage doubles a woman's chance of survival. Thanks to people like Kath, we are able to continue raising awareness, funding life-saving research and supporting women living with ovarian cancer.

Want to join Kath this March? Try these...

- **Bake Some Noise** – Invite family and friends for afternoon tea, or whip up some tasty treats for work colleagues.
- **The Big Colour Clash** – Join hundreds of people at work and school on 10 March and wear your most outlandish outfits for a donation.
- **Noisy Nights** – turn up the volume with a disco, karaoke sing along – or why not go big with a fundraising ball?
- **Challenge 50** – Raise money and awareness – we'll send you 50 pin badges and wristbands to give out for a small donation.

To find out more, visit targetovariancancer.org.uk/march



Keeping the story going

The Beatles, the internet, sequencing the human genome: the legacies of recent generations are as varied as they are brilliant. But have you ever thought about what kind of legacy you want to leave behind?

At Target Ovarian Cancer we'd like our legacy to be about saving lives. But we can't do it alone.

Legacy gifts help us support women and their families, raise awareness of the symptoms of ovarian cancer and fund life-saving research. We have achieved so much over the past few years, but we know that there is much more left to do.

A gift in your will could make a lasting difference to the lives of women living with ovarian cancer.

If you have any questions, or have already left a gift in your will and would be happy to tell your story to inspire others, email legacy@targetovariancancer.org.uk or visit targetovariancancer.org.uk/legacy

A huge thank you

Thank you to all of our fantastic fundraisers! Keep sending in your pictures...



Estilla and friends conquered their Mount Snowdon challenge!



Rachel and Paul supported us on their big day.



On her 80th birthday, Do did a wing walk and raised over £1000!

Find out more and take on your own fundraising challenge: targetovariancancer.org.uk/challenges

Support us at your celebration: targetovariancancer.org.uk/celebrations

Ready for a challenge?

Take on a challenge and fundraise for Target Ovarian Cancer in 2017. Walking, cycling, running, at home or abroad – there's something for everyone!



CALENDAR 2017



Spring

Adidas Silverstone
Half Marathon

Edinburgh Marathon
Festival

Great Manchester
Run 10k

Vitality London 10,000

Isle of Wight Challenge
25, 50 or 100km

London to Brighton
Challenge 25, 50 or 100km

Summer

Vitality British 10k

Ben Nevis Trek

Cotswold Way Challenge
25, 50 or 100km

London to Paris Bike Ride

Prudential RideLondon–
Surrey 100

South Coast Challenge
25, 50 or 100km

Autumn

Great North Run

Richmond Running
Festival

Royal Parks
Half Marathon

Thames Path Challenge
25, 50 or 100km

London Marathon Walk

Dalai Lama Trek

Sign up now at
targetovariancancer.org.uk/challenges

Or visit targetovariancancer.org.uk/doyourownthing
to find something a bit different.

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There are
loads more
challenges to
choose from!