

News from Target Ovarian Cancer

On Target

July 2016



**Ask the
Experts**

**Pathfinder
2016**

**The Ovarian
Cancer Walk**



**TARGET
OVARIAN
CANCER**
For every woman. For life.

Welcome



The first half of 2016 was an extremely important time for raising much-needed awareness of ovarian cancer. After a fantastic Ovarian Cancer Awareness Month in March, we followed up with a successful World Ovarian Cancer Day on 8 May.

In this issue of On Target you'll also hear about our work across the four nations of the UK – the first ever ovarian cancer awareness initiative in Wales, our successful Being Together event in Northern Ireland, the new Scottish Cancer Strategy and England's Cancer Drugs Fund reforms. It's a great privilege to be able to work with you in all corners of the UK.

Looking forward, we'll be providing important new information on the experiences of those living with, and working with, ovarian cancer when we publish Pathfinder 2016 later in the year.

Here's to everyone who has helped us to raise awareness of ovarian cancer so far this year. Thank you, and let's keep it up!

Annwen Jones
Chief Executive

Inside this issue...

News:

Ovarian Cancer Awareness Month 2016, Ask the Experts conference and lots more **3**

Campaigns corner:

Pathfinder 2016 – why is it so important? **5**

Across the UK:

What's happening where you are **6**

Target on:

Research and lifestyle choices **8**

Get involved:

Summer days **10**

Get inspired:

Pay tribute to someone you love **10**



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



020 7923 5470



info@targetovariancancer.org.uk



targetovariancancer.org.uk



TargetOvarianCancer



@TargetOvarian

Cover image:
Fundraiser Ellie takes part in
Dress Louder during Ovarian Cancer
Awareness Month

News

Ovarian Cancer Awareness Month 2016: We were heard

Back in March, we marked Ovarian Cancer Awareness Month by asking you all to Start Making Noise and shout about the symptoms of ovarian cancer.

Hundreds of you took up our call – organising events all across the UK. From dazzling dresses and outrageous outfits, to brilliant bake sales and spectacular skydives, thanks to your noisy efforts, we raised over £85,000! You also helped more than two million people across the UK learn about the symptoms of ovarian cancer.

We'd like to take this opportunity to say a huge thank you to everyone who took part. Your hard work means together we will improve early diagnosis of ovarian cancer, giving women who have had a diagnosis a better chance of a longer, healthier life.

To see highlights, visit targetovariancancer.org.uk/startmakingnoise



United for World Ovarian Cancer Day



In May, 13 of our amazing supporters took on the challenge of a lifetime and set out to walk the Great Wall of China. The explorers finished their jaw-dropping trek on 8 May – and marked World Ovarian Cancer Day by restoring part of the Great Wall and placing a brick as a symbol of hope.

The theme for 2016 was #KnowNow, and across the world people talked about “What I know now...” We shared words of advice, guidance and even cautionary tales to answer the question: “If you knew then what you know now, what message would you share?”



“It was an honour to be part of the Target Ovarian Cancer team on World Ovarian Cancer Day. For me, if I knew back in my 20s what I know now, I would have made financial plans for when I got older!”

Donna

As one of the founding members of World Ovarian Cancer Day, we are proud to be able to join forces with other ovarian cancer charities and take part in this global movement.

News

Ask the Experts

In June, we travelled to Birmingham for our inspiring Ask the Experts conference. The event saw renowned clinicians come together to answer your questions about topics such as new research, genetic testing, advances in surgery and personalised treatment.

The event was also streamed live, so if you were unable to join us don't worry, you will be able to watch videos from all of the sessions by visiting targetovariancancer.org.uk/birmingham

Do you have a question about living with ovarian cancer?

Our Clinical Advisory Panel is here to help. From oncologists and clinical nurse specialists to psychologists and finance gurus; we can offer advice to help you. To find out more, please visit targetovariancancer.org.uk/experts, or call the Supportive Services team on 020 7923 5475.



Save the date

Do you want to meet other women living with ovarian cancer, get support or learn about the latest treatments?

Over the next few months, we'll be holding Being Together days in Middlesbrough, Lancashire and Hertfordshire. The events will feature workshops on living well, diet and relaxation:

Middlesbrough 22 September

Lancashire 11 October

Hertfordshire 8 November

Being Together days are an important chance for people whose lives are touched by ovarian cancer to access support and guidance. For more details, visit targetovariancancer.org.uk/beingtogether or call the Supportive Services team on 020 7923 5475.

Campaigns corner

Launch of Pathfinder 2016

This autumn we head to Westminster for the launch of our latest Pathfinder report.

Pathfinder is Target Ovarian Cancer's groundbreaking research that provides a detailed picture of the experiences of people living and working with ovarian cancer. It will be a definitive snapshot of the UK's ovarian cancer landscape in 2016.

Findings from Pathfinder 2009 and Pathfinder 2012 shaped government policy and drove Target Ovarian Cancer's ambitious programme of work.

Pathfinder 2016 will include five surveys – each with a specific focus:

- Our **survey of women with ovarian cancer** will help provide a picture of women's experience of diagnosis, treatment and care across the UK.
- The **Cancer Awareness Measure** will help us understand awareness of the symptoms of ovarian cancer among women in the general population.
- Our **GP survey** will map GPs' knowledge and experience of diagnosing ovarian cancer.
- Our **survey of Clinical Nurse Specialists** will help show what is happening on the front line of ovarian cancer treatment.
- Our **family and friends survey** will find out more about the needs of those close to a person diagnosed with ovarian cancer.

We'll be launching Pathfinder 2016 at the Houses of Parliament in November 2016. To learn more about the study, visit targetovariancancer.org.uk/pathfinder

This research is made possible by the kind generosity of The Peter Sowerby Foundation.



"Pathfinder is a chance for women who have been diagnosed with ovarian cancer to make their voices heard on a national level. Pathfinder 2016 will show what needs to change if we are to improve awareness and diagnosis of and treatment and care for women with ovarian cancer."

Christine, member of Pathfinder Advisory Panel

Where you are



Action across the UK

Want to know what's happening where you are? From new awareness campaigns to Cancer Drugs Fund proposals, here's all the latest ovarian cancer news from across the UK.

Scotland: New cancer strategy

In March, the Scottish Government launched their brand new cancer strategy.

The strategy, which pledges £100 million to improve prevention, early diagnosis and cancer services, also recognises the importance of specialist care, and commits the Scottish Government to funding genetic research into ovarian cancer.

This latest announcement follows important guidelines laid out in 2013 for the diagnosis of ovarian cancer in Scotland. Under the recommendations, CA125 blood tests and ultrasounds are carried out simultaneously, while Avastin (bevacizumab) is approved for use by the Scottish Medicines Consortium in some cases.

For more information, visit targetovariancancer.org.uk/scottishcancerstrategy

England: Cancer Drugs Fund proposals

Under proposed changes to the Cancer Drugs Fund, drugs like Avastin (bevacizumab) might not be available to women diagnosed with ovarian cancer in the future.

We want to make sure that it is. But we can't do it alone.

That's why we asked you to get in touch with your MP and let them know about the changes and the risks they pose.

So far, over 600 of you have written to your local MP. Thank you!

To find out more about the proposed changes, visit targetovariancancer.org.uk/cdf



Wales: We give GPs vital info ahead of launch of national awareness year

During this year's Ovarian Cancer Awareness Month, we joined forces with the Velindre Cancer Centre in Cardiff, to launch the very first Welsh ovarian cancer awareness initiative.

We were able to give every GP in Wales a toolkit containing our symptoms posters and leaflets – both in English and Welsh – and provide them with information about our online GP training modules.

Wales' Official Ovarian Cancer Awareness Year followed hot on the heels of the awareness initiative, and was launched on 8 May, World Ovarian Cancer Day. The campaign, masterminded by the late Annie Mulholland (pictured above), aims to make every woman in Wales aware of the symptoms of ovarian cancer in a year.

Diolch i gyd am helpu i wneud i hyn ddigwydd - Thank you all for helping to make this happen.

A personal perspective...

Northern Ireland: Being Together day

Back in March, we were in Belfast for one of our Being Together support days. Ann Adair attended the event and told us how she got on...

"It was wonderful to have a Being Together day in Belfast. This gave women the opportunity to meet others with the disease and for some, it was the very first time they had spoken to anyone else with ovarian cancer.

"I was proud to give a speech about my experience of diagnosis and treatment and then all of the amazing things I've done since – campaigning at Stormont and Westminster, speaking to the media and fundraising.

"There was a good selection of workshops to attend. In the Ask the Experts session, we heard about a new clinical trial that has been developed in conjunction with Queen's University Belfast. Various questions were asked of the panel and we got some really interesting answers.

"On behalf of all of us, I would like to thank Target Ovarian Cancer for coming across to Belfast to support us in this way. It will have made such a difference for the women who attended."



Target on

Lifestyle choices and ovarian cancer

In 2014, Anne Ainsworth, 55, was diagnosed with ovarian cancer. Here she talks about the modern minefield of 'lifestyle risks' and asks whether they might be linked to the disease...

After being diagnosed with ovarian cancer, I started reading about the possible risk factors. I wondered whether they could explain why I had developed the disease. From reading Target Ovarian Cancer's information pages, I'm aware that age and family history are big risk factors for ovarian cancer.



"The risk factors seem a bit random. It feels like we are getting blamed for getting cancer."



The more I read, the more confusing it seemed. You were more at risk if you had no children, hadn't breastfed and had early onset and late cessation of periods.

It also looked like being tall, having irregular periods and a BMI greater than 25 put you at risk.

I suppose I'm thinking that the risk factors seem a bit random. It feels like we are getting blamed for getting cancer.

I would like to know whether my lifestyle really helped cause my cancer, and could I have done anything to prevent it?

Target Ovarian Cancer, says:

We hear a lot in the news implying your lifestyle choices may have put you at risk of cancer. Many of these stories are misleading, misreported or plain wrong.

A direct link between lifestyle choices and causation does not exist for most cancers.



The two biggest risk factors for ovarian cancer are age and family history – neither of which are lifestyle choices.

Reports in the media are about associations between lifestyle choices and an increased risk of a cancer. They are not proof of causation. These reports are usually based either on large studies asking people to recall multiple lifestyle choices they have made, often going back many years, or on treating cancer cells in a laboratory with high concentrations of a particular chemical.

A key point to remember is that most cancers will not have a single cause.

We know that 4 out of 200 women develop ovarian cancer over their lifetime. The various 'lifestyle factors' (talc, HRT, IVF, child bearing, BMI, height) only alter this small risk very slightly.

For example, if 200 women used talc on their genitals regularly, five rather than four would be expected to develop ovarian cancer.

Even if you had multiple lifestyle risk factors, these only impact slightly on your inherent risk of ovarian cancer. So whilst 'lifestyle choices' can play a small part, the two biggest risk factors for ovarian cancer are age and family history – neither of which are lifestyle choices.

In summary, please be reassured the vast majority of ovarian cancers are not attributable to any lifestyle factor, and no lifestyle factor can be said to be causative. If this has raised more questions for you, please get in touch with us. You can also visit our website to read more about ovarian cancer risk – targetovariancancer.org.uk/riskfactors

Research grants announced

Target Ovarian Cancer recently announced the awards for our UK-wide research grants programme. This is essential and groundbreaking work for the charity. We are thrilled that the following recipients have been awarded grants to help further their research:

The **Innovation in ovarian cancer research award** goes to Professor Iain McNeish at the University of Glasgow. This study will look at new treatments for ovarian clear cell carcinoma, a type of ovarian cancer. Professor McNeish and his team at the University of Glasgow have been awarded £180,000 to conduct the research over 28 months.



The **Supportive and palliative care research award** goes to Dr Agnieszka Michael at the University of Surrey. This research will investigate whether a liquid nutrition drink could help women with a diagnosis of ovarian cancer that have an inoperable bowel obstruction. Dr Michael and her team at the University of Surrey have been awarded £65,000 to work over 36 months.

Research such as this is only possible thanks to the funding we receive from individuals, trusts and legacies. Leaving a gift in your will is the ultimate way to help us fund them. Find out how you can leave a legacy at targetovariancancer.org.uk/legacy

Get involved



Summer Days

Would you like a chance to shine this summer? We want to make sure every woman knows about the symptoms of ovarian cancer, but we need your help...

This summer join together with family, friends, colleagues and neighbours for a sizzling summer get-together. Whether it's a donation for a barbecued burger or some pennies for a potted plant, the money you raise could help to reach women across the UK with information on the symptoms of ovarian cancer and provide GP training, so that more women are diagnosed earlier.

"We had a really successful open gardens day – the sun shone for us and it was a great party atmosphere!"

Jill



Stuck for ideas? Why not:

- **Throw a garden party:** Make the most of the sunshine by firing up the BBQ, packing a picnic or organising a garden event for your street.
- **Dress Bright:** Feeling a bit more adventurous? Why not bring the sunshine to your office or classroom? Just grab your most colourful Hawaiian shirt, and ask your colleagues to dress for the summer and donate £2. Stick up a symptoms poster, hand out leaflets or display some pin badges to share information on the symptoms of ovarian cancer.
- **Get Sporty:** Is your team in a league of their own? Could you top the fundraising tables? Local sports clubs up and down the country will be holding charity fixtures and organising bucket collections.

However you'd like to get involved, just get in touch and we'll send you a free Summer Days starter pack, along with all the materials you'll need to make your event a dazzling success!

To find out more, visit targetovariancancer.org.uk/summerdays or call the team on 020 7923 5474.

Pay tribute to someone special

Make a donation in memory of a loved one and help create a legacy for the future.

Losing someone you love can be devastating. For many people, doing something positive can provide comfort and help them deal with their loss.

Giving a gift in memory of a loved one is a beautiful way of honouring someone special and celebrating their life.

Maybe you'd like to ask for donations instead of flowers at the funeral, create an online tribute fund or dedicate a brass leaf on our Tribute Tree. Whatever your choice, a gift given in tribute can help us continue supporting thousands of woman living with ovarian cancer, both now and in the future.

For more information, please visit targetovariancancer.org.uk/giveinmemory, or call our team on 020 7923 5474.



A personal perspective...

Celebrate and save lives

Support us on your special day and help us give women with ovarian cancer the ultimate gift.

Birthdays, weddings, retirements and anniversaries: whatever the occasion, your friends and family can make a real difference to the lives of women living with ovarian cancer.

Kelly Ann got married in Carrickfergus in 2014, and ordered pin badges for female guests on the day. She says, "I lost my beautiful cousin to ovarian cancer a few months before our wedding, so we made a donation and provided the ladies with pin badges to wear. Each badge came with a little card with the symptoms of ovarian cancer, so it was a great way to include Oonagh in our day and amazing to raise awareness of the symptoms of such a devastating disease, while supporting the great work that Target Ovarian Cancer does."

For more information, visit targetovariancancer.org.uk/celebration





The
Ovarian
Cancer
Walk

Taking steps to beat
ovarian cancer

Queen Elizabeth Olympic Park, London –
9 October 2016
and

Holyrood Park, Edinburgh –
16 October 2016

Walk or run, 10k or 5k
targetovariancancer.org.uk/walk
020 7923 5474

**£5 off for
On Target
readers!**

Register NOW
to get £5 off when
you join The Ovarian
Cancer Walk 2016

Visit targetovariancancer.org.uk/walk
and enter offer code
ONTARGET16 when you sign up

Reader offer is valid until 31 July 2016.
Visit targetovariancancer.org.uk/walk
for more details.



TARGET OVARIAN CANCER
For every woman. For life.