

Jo's cervical
cancer trust



On the road to eliminating cervical cancer

Impact report 2018

Every day, nine
women are told they
have cervical cancer.

Two die from it.

We're fighting to
make cervical cancer
a disease of the past
and we're determined
to get there as soon
as we can.

We're the only UK charity dedicated to cervical cancer and we're here for every woman who needs us, for as long as they need us.

By 2022, we have set ourselves some ambitious goals:

10%
fewer cases
of cervical
cancer in
the UK

80%
of women
taking up
their cervical
screening

92%
of girls taking
up their human
papillomavirus
(HPV) vaccination,
providing protection
against 70% of
cervical cancers

100%
of women told
about Jo's Cervical
Cancer Trust on their
cervical screening
invitation, enabling
them to access support
and information to
make decisions about
their health

66%
of women
diagnosed with
cervical cancer
made aware of the
charity and the
crucial support
we can offer

During 2017/18 we have been working hard to make progress towards these targets. We can't do it alone and it is only through collaboration and partnership that we will get there. This impact report provides insight into what we have achieved during the year – all thanks to your incredible support.

Welcome from Steven



In 2017, Steven's wife Laura was diagnosed with cervical cancer. In a tragic coincidence and despite there being no genetic link, her mum had lost her life to the disease five years before. Here Steven explains the devastation the disease has wreaked on his family and what Jo's has done to help him and thousands of others this year.

Laura's mum had always been for her smear tests through her fifties but, in her sixties, they started to drop down her priority list. At 63 she noticed some bleeding. Sadly it was discovered she had cervical cancer. It was very advanced and she was given just six to eight weeks to live.

“ The doctor laid out the treatment options and said the safest would be a radical hysterectomy. ”

Five years on, Laura's smear test came back with abnormal cells. Her doctor sent her for further tests and unfortunately she was given a cervical cancer diagnosis. It had been caught early, but it was growing very quickly. The doctor laid out the treatment options and said the safest would be a radical hysterectomy, but that would depend on whether we wanted more children.

We already had Harry, who was two and ultimately decided that Laura being a mother for as long as she could to the child we had was most important. She signed up for the hysterectomy on the Monday. That Friday, we found out she was pregnant.

It was an extremely difficult decision, but keeping the baby would have reduced Laura's chances of survival, and she would have had to have chemotherapy while pregnant. Laura had a medically-managed miscarriage, sitting in a dingy hospital room for 18 hours taking tablets. It was awful.

Her hysterectomy went well. It's about as intrusive an operation as you can have, and the recovery was rough. But now she's back at work and fit as ever.

Support from Jo's

Right from the moment Laura was told there might be a problem, Jo's was there for her. We found support on the website and the online forum – this was really useful when information was whizzing over our heads in medical appointments. Laura was on the site virtually every day.

It became even more important when she was diagnosed and was looking at the different treatment options, and how the pregnancy might be affected.

It also let us know that we weren't alone. You think you're the only person this is happening to, but if you look at the Jo's site, you can find someone who's been through something very similar and is now doing well. It makes you think you can too. Going to Let's Meet events and meeting others face-to-face has also helped with this.

A great year

Jo's has also worked hard to prevent others from facing a cervical cancer diagnosis, by promoting the ways women and girls can reduce their risk.

Spreading the word is so important. Cervical cancer shouldn't be affecting as many people as it does. Encouraging women to go for smear tests has become a bit of a passion for me. Jo's has come to my workplace to give talks. Hearing that women have gone for tests as a result of hearing about Laura is amazing. It's helped get me through it.

Thank you to everyone who has donated, campaigned or fundraised this year. You've literally helped to save lives. I hope you'll continue to support Jo's until we can eradicate cervical cancer for good, and every woman going through this disease gets the support they need.

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“ Hearing that women have gone for tests as a result of hearing about Laura is amazing. ”

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1,535
people
supported
through our
helpline

95,000
people
brought
together on
our online
forum

3
new reports
launched
highlighting
where action
is needed
to reduce
the impact
of cervical
cancer

385%
more
Instagram
followers
19% more
Facebook
followers
21% more
Twitter
followers

millions
reached
about the
importance
of screening
and
vaccination
during
Cervical
Cancer
Prevention
Week

2.4million
website
sessions,
arming women
with the
information
they need to
feel more in
control

389,694
printed
information
materials
distributed

4,826
people
spoken to
at our Be
Cervix Savvy
Roadshows
about how
to reduce
their risk
of cervical
cancer

1,833
media
pieces
raising
awareness
to millions
about every
aspect of
cervical
cancer

hundreds
of politicians
supported our
work in their
parliaments,
on social
media and in
the press





Supporting women through their most difficult times

“The wait for the LLETZ result was mentally tough, especially four days after treatment when I fell ill with an infection. I’m so very lucky to have an incredible network of family and friends to rely on. The Jo’s forum was full of women sharing similar experiences and this was immensely helpful to read.”

Every year, more than 3,200 women face the fear, shock and confusion of a cervical cancer diagnosis. Another 220,000, like Lisa above, are told they have cell changes or cervical abnormalities, often requiring invasive treatment.

We’re here with the support they need, every step of the way.

This year:

- Our helpline took **1,535** calls, giving expert information and a friendly, empathetic ear. **95%** of callers said they’d use the helpline again.
- To make sure they’ve got all the support and information they need, we offer a second call to helpline callers a few weeks later. **We called 364 people back** in 2017/18 and **100%** said it was useful, we also made **26%** more callbacks than last year.
- Sometimes, nothing beats talking to someone who knows what you’re going through. Our online forum enabled more than **95,000 people** to come together in 2017/18 to talk about all things related to cervical cancer and abnormalities.
- We brought **68 women and their partners** together face-to-face at Let’s Meet, our annual support and information day in London, with **83%** saying they felt more hopeful afterwards. Another **41** came to our Mini Meet in Glasgow.
- Our expert, peer-reviewed information helped to answer questions, dispel myths and empower people with knowledge. We distributed **389,694 printed information materials**, a **39%** increase on last year.
- **Our website is full of information and supportive resources and there were 2.4 million sessions** in 2017/18.
- **1,757** people also used our Ask the Expert service, asking questions online which health professionals – volunteering their time – answer.



“The website was really informative”

Stephanie’s story

I was invited for a routine smear test just before my 25th birthday. I didn’t have any symptoms so had no reason to think anything was wrong.

I wasn’t scared when I was told I had abnormal cells as lots of women have them, however just a few weeks later, I was called in to receive the devastating news that I had cervical cancer. I remember being in the waiting room afterwards and I couldn’t speak. I just wanted to know what was going to happen next.

I was given two treatment options: a hysterectomy or trachelectomy. I chose a trachelectomy because I want to have children in the future.

I had chemotherapy first after being advised this would more likely stop the cancer from coming back. It sounds silly but the worst part was definitely losing my hair. I then had the trachelectomy operation and my Dad came with me – it was the first time I’d ever seen him cry.

“Jo’s is the only charity specialising in cervical cancer, so they need as much support as possible.”

It’s been nearly two years since I got the all-clear, but I still suffer with side effects. I get tired very easily and my feet can give me cramp-like symptoms.

I found out about Jo’s when I was first diagnosed as I was given a leaflet in a pack I was given. I found the website really informative, and reading the stories of other women who had been through similar experiences made me feel less alone.

I also went to Let’s Meet this year. It was an excellent day and I found it really useful meeting other people who have been through the same as me. The workshops were great too – there was one on mental health and I related to everything the speaker said.

Jo’s is the only charity specialising in cervical cancer, so they need as much support as possible to keep doing the amazing work they do. If I hadn’t found them my experience would have been so much tougher.

“ I was called in to receive the devastating news that I had cervical cancer. ”

Preventing cervical cancer, saving lives.

Eradicating cervical cancer is our ultimate ambition – and it's far from just a pipe dream.

Launched in December, our model shows that cervical cancer in young women could drop 75% by 2040, with deaths close to zero. We commissioned a team at Queen Mary University of London to look at incidence and mortality among different age groups as a result of changing screening and vaccination rates. Worryingly we found 62% more women aged 50-64 are at risk of developing of the condition – which could lead to a 143% rise in deaths.

This provided us with the focus we needed to develop and launch our new five year strategy taking us to 2022.

We need to work hard to reduce the impact of cervical cancer at every age. This means raising awareness of screening and vaccination and campaigning for innovation to improve the programmes that we have.

This year:

- We reached **45.7 million people** – more than ever before – with messages about the importance of screening and vaccination during Cervical Cancer Prevention Week, with many laboratories reporting surges in attendance of smear tests.
- We conducted research which highlighted embarrassment as a barrier to smear test attendance among young women and encouraged conversation to help tackle the fears and stigma that exist. We launched a blog series, 'Let's Talk About it', exploring a wide range of barriers and providing tips and information, this includes a previous bad experience, anxiety and screening for survivors of sexual violence.



“In my 21 years of working in a lab I have never seen it so busy”

“You don’t know how much better I feel having spoken to you. I know that I can take the first step now”



- Our social media campaign #SmearForSmear, asking people to post photos of themselves with smeared lipstick to promote smear tests, trended on Twitter, with support from **86 celebrities** and **135 influencers**. We secured **908 media pieces** amplifying our messages to women of all ages.
- We ran our second Be Cervix Savvy Roadshow, visiting **12 high streets and retail parks** across Scotland. **28 volunteers** gave **273 hours** of their time to help us speak to **4,826 people** about cervical cancer and prevention. Funded by the Scottish government we visited locations where screening attendance is lowest. This was double our original target of **2,740 people** and means thousands more women now understand how they can reduce their risk. The Roadshow also allowed us to improve relationships with health and policy colleagues across the country, including with Health Boards, colposcopy departments, local public health teams and members of parliament including the Cabinet Secretary for Health who visited.
- We were featured in **1,833 media pieces (47% more than last year)**, each one raising awareness about cervical screening and HPV vaccination, as well as providing insight into life with and beyond cervical cancer
- We reached millions through our social media. Our **Facebook followers rose 19%**, our Twitter followers **21%** and our Instagram followers **385%** compared to last year. Our Facebook posts alone reached **4.5 million people**.



- Cervical cancer in women over 50 is increasing while screening attendance is falling so we created a campaign to encourage this group to get screened, distributing **480,000 targeted leaflets** to GPs around the country.
- We appointed **2 new public health engagement coordinators** in Glasgow and London, who are working hard to increase cervical screening by delivering training, working with local communities and supporting primary care services.
- We launched lesson plans in partnership with Teenage Cancer Trust for teachers to use with year 8s and 10s to increase their awareness of HPV and its link to cervical cancer. They were viewed **1,028 times** providing a vital resource to impart life-saving messages from a young age.
- We undertook research to better understand different groups' knowledge and barriers to cervical screening, enabling us to develop targeted information and campaigns. This included women over 50, women who have experienced sexual violence, South East Asian women and LGBT women and people with a cervix.



“I was one of these people who missed two smear tests. I’ll never know whether that would have stopped the cancer”



Sharon’s story

It all began after a chance conversation at a ladies networking lunch where someone told me her daughter had been diagnosed with cervical cancer. I said I’d missed two smear tests and hadn’t been for 6.5 years. She made me promise to go.

Ten days after my test I got a letter saying I had abnormal cells and needed to go for a colposcopy. I went home that night literally thinking I was going to die. I looked up cervical cancer and the first website I found was Jo’s. I never looked anywhere else after that – Jo’s was my lifeline.

After the worst Christmas ever – my mum was also terminally ill – the consultant called me in and told me I had a tumour. We decided the best treatment was a radical hysterectomy. I was 47.

Surgery went fine and thankfully they got everything.

Cancer affects you for the rest of your life but I feel incredibly lucky; lucky that I had the chance conversation, and lucky my cancer was caught at stage 1. Recovery was slow though. Fatigue hit me big time for months afterwards. I felt like a zombie.

“ I felt strongly that I wanted to do something to help Jo’s and spread the word about the importance of smear tests. ”

I felt strongly that I wanted to do something to help Jo’s and spread the word about the importance of smear tests. I volunteered on the Roadshow in Scotland and I’ve told my story in the media.

Any embarrassment I felt about sharing my story was overcome by the thought that if one woman went for a smear test after reading it then it would all be worth it.

I missed two smear tests and I’ll never know whether that would have stopped the cancer. A smear test takes two minutes and it could stop you going through what I have.

We need to make sure more women understand they can literally save your life.

“ Ten days after my test I got a letter saying I had abnormal cells and needed to go for a colposcopy. ”

Influencing policy change to improve and protect health

We believe that women with cervical cancer deserve the best possible treatment and support.

We also know that through cervical screening and vaccination we will achieve our vision of eliminating the disease, saving thousands of lives.

Making both happen partly lies in the hands of decision-makers from MPs to NHS leaders. That's why we strive to influence the people who can make a difference.

This year:

- Our Computer Says No research report found worrying inequalities in access to cervical screening across the UK with **1 in 8 women** finding it difficult or impossible to make an appointment, and declining availability through sexual health services. We demanded change during Cervical Screening Awareness Week, with **6 recommendations** for policy-makers including:
 - An **audit** to assess what more can be done to ensure all women can access cervical screening at a location, time and service appropriate to them.
 - An immediate **review of the IT** system in England to ensure it is fit for purpose, safe and future proofed.
 - An integrated approach to commissioning and delivering screening must be taken across primary care and sexual health with the introduction of a national budget in England.
 - Funding for large-scale pilots on **self-sampling**.





- The campaign received **98 pieces of media coverage**, while **73 politicians** UK-wide backed our calls and we are working with stakeholders including Public Health England, NHS England and the Scottish Government to take each recommendation forward.
- Our research report Cervical Screening in the Spotlight: One Year On called for action. A quarter of local authorities and almost a fifth of clinical commissioning groups said they undertook activity to increase cervical screening attendance as a result of our 2017 report. However we found **32% of local authorities and 34% of clinical commissioning groups** had not done anything in the past year. With attendance in England at a 20 year low, we used the report to provide tips and recommendations for local areas sending it to Public Health England and NHS England stakeholders, and to all directors of public health.
- The long-term consequences of cervical cancer treatment – including fertility, bowel and bladder difficulties, fatigue, pain and mental health problems – are often underestimated. Launched in September, our report consisting of the largest known dataset of women living with and beyond cancer, highlighted that while **83%** of women had experienced long-term problems, far fewer had had the treatment they needed. We set out several recommendations for change to speed up diagnosis and treatment of the long term consequences of cancer and brought together key health and policy stakeholders at a **roundtable event** chaired by then Chair of the All Party Parliamentary Group on Cancer John Baron MP.
- **98 politicians** across the UK supported Cervical Cancer Prevention Week across social media, in the media and by raising the topic during Prime Minister's Questions and First Minister's Questions in Scotland.
- We want decision-makers to take action all year round, not just in our campaign weeks. We met with **34 MPs in Westminster, 16 Members of the Scottish Parliament and 19 Welsh Assembly Members** in 2017/18 encouraging them to take action to improve health outcomes for women. In all 4 countries of the UK, we also sat on groups shaping policy including the cervical screening boards, helping to influence key national decisions.

“We need to get more politicians on-side”



Maria's story

In April 2010 I started to have irregular bleeding but didn't think much of it. By August I was bleeding almost constantly and I was in a lot of pain. In October I was told I had cervical cancer, I was 25. The doctor recommended a hysterectomy so I had to face losing my fertility which was really tough. I already had one son and one of my doctors gave me the best piece of advice: to focus on him, the child I have, not the ones I might had had.

After the operation, I found out I also had to have chemotherapy, radiotherapy and brachytherapy. I cried for days. Treatment made me so very tired and I would be up at 7am for my appointments and in bed by 6pm most nights, I had no energy.

My biggest issue was going through the menopause. I suffered badly with hot flushes, yet very cold hands and feet. Jo's helped me so much. I used their website and resources all the time. Doctors often don't have much time during appointments, so Ask the Expert really filled a gap and helped me understand what I was dealing with.

Several years on, I still get tired very easily, and tend to get a lot more colds due to a reduced immune system. I'm rugby-mad but can't play anymore which is tough.

“ I decided I wanted to give something back to the charity. ”

When I had my all clear I decided I wanted to give something back to the charity. I've done a sponsored abseil and skydive and I am a media volunteer so often tell my story of living with and beyond cancer. We need to get politicians on-side. They're the ones who set policies about screening and there is so much they can do to encourage others to take action.

This year I volunteered at a drop-in event at the Welsh Assembly this year. It was fantastic – I spoke to Assembly Members about my experience and why we need more women people to know how they can reduce their risk of cervical cancer – I think it really helped get the message across. If we work together we can make sure fewer women have to go through what I did and that means so much to me.

“ By August I was bleeding almost constantly and I was in a lot of pain. In October I was told I had cervical cancer, I was 25. ”

Our Fantastic Funders and Fundraisers



All of our income comes from fundraising. Put simply, without the support of individuals and funding organisations that have donated to Jo's this year, we would not have been able to carry out our vital work.

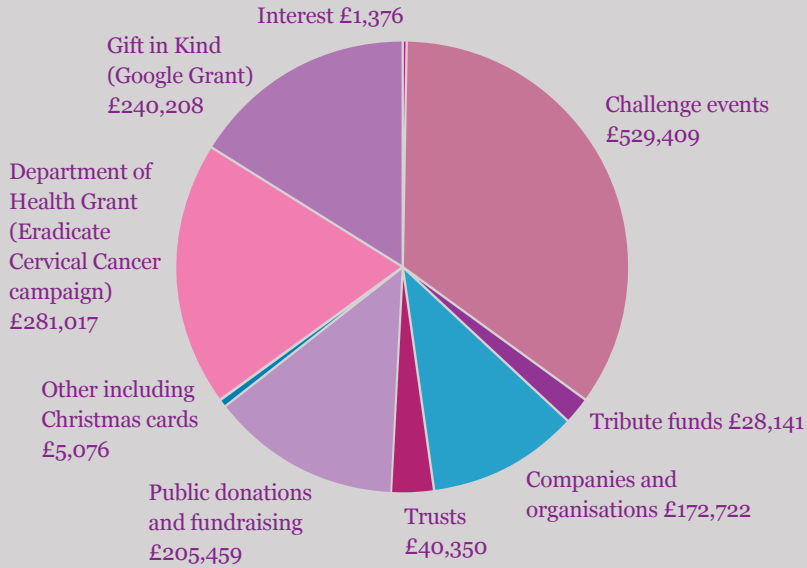
Many of our fundraisers have had experience of cervical cancer either directly, or from watching a loved one contend with the disease, or they may be one of the many health care professionals who tackle the disease in a professional capacity.

We are so humbled and appreciative for all their efforts. It is only because of our incredible fundraisers and funders that we are able to do what we do. We would like to say a huge thank you.

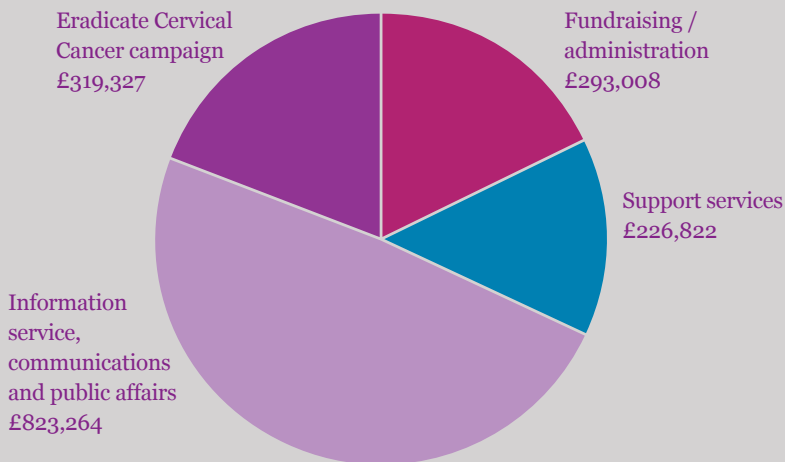
- **More than 3000 women raised over £500k** through Women V Cancer cycling events.
- **Over 250 individual fundraisers** did all sorts of things to raise funds, from organising art exhibitions to driving across Mongolia with no GPS in an old 1 litre car.
- **Over 100 participants raised over £20,000** at Steps for Jo's at the Olympic Park in June.
- **Income from Trusts increased by 40%** with grants from new funders such as the February Foundation.
- **£124,000 from the Sottish Government** for research and a Roadshow in Scotland in areas with low screening uptake.
- **UCLH Cancer Collaborative invested £42,000** in an awareness-raising campaign in East London, incorporating social media and bus advertising.
- Facebook launched its fundraising function in January 2017 and **228 supporters** used it to ask for donations instead of birthday presents raising **£34,937.45**.

How we raised and spent our money

Income 2017–18



Expenditure 2017–18



Jo's cervical
cancer trust



You made
it happen!

Help us make cervical cancer a disease of the past:

Volunteer

jostrust.org.uk/volunteer

Campaign

jostrust.org.uk/campaign

Donate

jostrust.org.uk/donate

Contact us:

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0808 802 8000

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