



# Annual Report

2020-2021

# Joanne

COVID made my whole experience so much harder. I was really wary of getting a smear test at first so put it off for a while, and then appointments just weren't available. The waiting was tough and I couldn't take anyone with me to the follow up tests and appointments, which made me feel really alone at times. I'm only 33 and I was shocked when I was told I had cancer and needed a hysterectomy. I wanted another child but that was suddenly taken away.

The operation was a really difficult experience, and all the COVID safety measures made me feel isolated. I wasn't really given any information about aftercare, it felt like I was just left to work it out on my own. I have anxiety, and it just felt like more and more things to try and deal with.

Thankfully someone pointed me towards Jo's. Jo's enabled me to find answers and to understand terminology that I wasn't familiar with. It's hard not knowing what was going to happen or what the particular procedures were, but Jo's had all that information and gave me comfort. Although you have the love and support off your friends and family, they don't always understand what you are actually going through. With Jo's they get it. They understand and can support you through it all.



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# We're Jo's Cervical Cancer Trust

**We're here for anyone who needs us, for as long as they need us. From first cervical screening to living beyond cancer, we're just a call or message away.**

Our community is at the heart of all we do, and they helped get us through a really tough year. The impact of COVID was shattering to Jo's. We lost 88% of our event income, and saw a significant drop in unrestricted income, we had to do everything we could to keep going. This meant letting go of our office, using the furlough scheme and stopping projects across the charity. However difficult the year was for us, it was nothing compared to how it feels to receive a devastating diagnosis whilst sitting alone, being unable to properly say goodbye to a loved one, not being able to access a therapy which was a lifeline or being faced with postponed operations, tests and appointments. This was the reality for many over the last year. The impact of COVID on cancer and prevention services has been stark and it hasn't gone away.

Our vision is for cervical cancer to be a thing of the past. Until we get there we want everyone to have the support they need.

COVID-19 has slowed our progress down but this year has been a year of rebuilding and recovery for Jo's. Our staff have worked incredibly hard to innovate and ensure those who needed us got the answers they needed. We listened to our community and used our voice to advocate for their needs. We're proud of our achievements this year, working with new partners, on new projects and expanding our reach even further.

Thank you to everyone who has raised money to help us, to everyone who has shared their experience and to all who have given us their ideas or their time. Thanks to you we are able to look forwards and are focused on building for the future. This year we are developing a new 5 year strategy to give us the focus, direction and stability we need to reduce the impact of cervical cancer in the UK. We're excited to see what this holds and we hope you'll join us on that journey.





# Why we're here

**Nine women** are diagnosed with cervical cancer every day in the UK, that's **3,200** a year

Sadly **two women** die from cervical cancer every day

Over **220,000** are diagnosed with cervical cell changes

One day cervical cancer can be a thing of the past. **We won't stop until we get there**



# How we're here

COVID stopped many fundraising events, but **hundreds of incredible supporters** took on their own challenges to help us continue to support those who needed us during a difficult year

**62 new media volunteers** joined the 100s who share their stories, helping others know their options and most importantly feel less alone. They helped us get **1,700 media pieces**

Our amazing **volunteer panel** responded to a **24% increase** in Ask the Expert submissions, which meant we could give answers to over 500 people more than the year before

Our first ever **legacy marketing campaign** resulted in **34 wills** being written through our partner Beyond, helping make Jo's a sustainable charity in the long term

Our **supporters** have used their birthdays to set up fundraising pages on Facebook and have raised over **£100,000** since it started!

We are extremely grateful to the **trusts and organisations** that supported us through such challenging times, increasing funding to unrestricted grants and supporting new projects

Our **virtual Steps for Jo's challenges** saw fundraisers lacing up their trainers and raising **£23,500**, up from £11,300 in the previous year.

Funding from trusts such as **The February Foundation, Childwick Trust** and **John Coates Foundation** helped us to deliver our Helpline services and make necessary upgrades to our website – vital services for many during the pandemic

Our new **In Memory week** in November 2020 gave fundraisers a place to remember and celebrate the lives of loved ones. **£35,600** was raised in the process compared to £15,000 in the previous year



# Because we're here

**2,524 calls** were connected to our Helpline with 91% saying they found the call helpful

Over **1.2 million people** visited our website over the year accessing answers, tips and connecting with others through our Forum. This included over **50,000 views** of our COVID Hub with information about going for tests and treatment in the pandemic

We were able to raise the needs of those living with **Pelvic Radiation Disease** in a report highlighting gaps in care and support for those affected. This has led to meetings with a wide range of professionals across the NHS to discuss this overlooked area and the development of a strategy to raise the issue further

Our new **1:1 service** for those living with and beyond cancer meant we could provide tailored, individual support at a time when services were being cancelled and paused

Women with a **learning disability** are less likely to attend cervical screening. To address this we worked with Enable Scotland to co-produce **5 films** which have already been viewed almost 3,000 times providing accessible information and tips

We carried out **research** identifying groups who were less likely to access cervical screening during the pandemic and worked with NHS England to support the recovery of the programme

We arranged a **live cervical screening** on Channel 4's Steph's Packed Lunch which helped to share tips and reassuring messages about the test to a wide audience when many were afraid to attend



# Charlene

I was diagnosed with cervical cancer at the age of 32. I had no idea what to say and was in total shock. Being told that you had to have chemotherapy and radiotherapy for six weeks, then brachytherapy, and going to and from the hospital was very overwhelming. It was stressful trying to get there on time and sorting out my children. Chemotherapy felt a bit like morning sickness, I couldn't sleep or rest. Having to tell my kids was hard. My little boy was really small and he didn't understand, telling my daughter would have just broken me so my mum told her in the end and thankfully she had fantastic support from her school.

There were times where I wanted to give up through this experience but in a way I am really grateful for having gone through all of this. I've had a better outlook on life since then, and I feel that I can achieve more than ever before. We have an amazing vaccination and cervical screening which can stop some cancers from ever developing. My daughter has had the HPV vaccination but there are so many people who still need to understand these potentially life-saving messages. Jo's are the charity who are working to educate and raise awareness in the UK and I want to make sure they can continue to do this.



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# Listening to our community

The impact of COVID on cancer and prevention services cannot be underestimated and the physical and emotional impact on our community was great. In order to provide the best possible support, and advocate for the needs of our community, we needed to find out how they felt.

Cancer referral figures fell by 60% at the height of the pandemic with fewer people seeking help for potential cancer symptoms. Thanks to funding from the Department of Digital, Culture, Media and Support we were able to conduct research which found only two in five knew any cervical cancer symptoms, with the lowest level of awareness among the 18-24 age group. We worked with our community to launch a campaign urging women and people with a cervix not to ignore symptoms. Over 24,000 accessed our campaign page with information they could trust.

Screening services across much of the country were paused or reduced at the start of the pandemic. Searches on Google for 'smear test' increased 123% from 33,100 in June 2020 to 74,000 in March 2021, clearly showing the need for information and support. Searches for 'colposcopy' increased by 82% to 40,500 in March 2021.

To support recovery of these vital programmes we worked with NHS England on a research project to identify how attitudes to screening were impacted. We identified a wide range of concerns including confusion about whether screening was happening and whether it was safe. We identified increased worries among groups of women such as Black, Asian and minority ethnic groups, and those shielding.

We worked with colleagues across the NHS to ensure those delivering screening knew how their patients felt, and provided resources for them to use to address anxieties. We worked with media to encourage women to not delay tests and treatments, this included an hour debate on the BBC Asian Network.

Calls to our Helpline remained high over the year. An additional five Helpline volunteers were trained, increasing the number of hours we were able to open the service, leading to an 11% increase in connected calls and 20% increase in callbacks.

## Do you know the symptoms of cervical cancer?

The most common symptoms include:



Vaginal bleeding that is unusual for you – after menopause, between regular periods or after sex



Unexplained pain in your lower back or between your hip bones (pelvis)



Pain or discomfort during sex



Changes to vaginal discharge

These symptoms are not usually cervical cancer, but it's important to contact your GP and get them checked out. Don't wait for cervical screening (a smear test).

If your GP asks you to go into the surgery, don't worry – they have measures in place to keep you safe from coronavirus.

For more information or support, call our Helpline on **0808 802 8000** or visit [jostrust.org.uk/symptoms](https://jostrust.org.uk/symptoms)

Charity Number: 1126620 Scottish Charity Number: SC041026



Our Helpline is a trusted resource and we were pleased to be able to use it to support NHS Scotland following an incident where high numbers were incorrectly ceased from screening following a hysterectomy. As a result, we used our expertise to provide emotional support and signposting at an incredibly difficult time. We continue to provide Helpline and communications support to the YouScreen team leading the biggest HPV self-sampling pilot in England.

Our Ask the Expert service supported 2,509 people, over 500 more people than the year before. We saw a 54% increase in submissions about HPV.

*Your experts have really put my mind at ease and I'm very grateful for the support.*

Our research at the start of the pandemic found a preference for online support and we were delighted to be able to relaunch our new email Helpline service, which had been paused in the previous year. We have had 181 emails since May, allowing us to provide reassurance and signposting to those who didn't want to pick up the phone.

As the UK's leading cervical cancer charity, supporting those living with and beyond cervical cancer is at the heart of what we do. During a challenging year for cancer services, we were determined to provide additional support to our community and were able to relaunch our 1:1 service in May, resulting in 42 sign ups who have had 35 sessions so far.

Thanks to some amazing funders, we launched a new Forum to replace our old, outdated offer leading to a 50% increase in daily engaged users in the first 60 days and enabling much needed connections, comfort and answers.

*The cervical cancer forum was immeasurably reassuring while waiting for my colposcopy results. You do such brilliant work.*

## Joe

After his wife found support at Jo's following her cancer diagnosis, Joe set himself the challenge of running the distance from Land's End to John O'Groats - a total distance of 1744km. To make it even harder, he's carrying a 35lb weight on his back!

Joe is currently at the halfway stage of his mammoth challenge and hopes to complete the challenge by next April.



COVID meant we couldn't meet in person, so we ran our first ever virtual support event in September with 92 sign ups, of which 74% hadn't attended previously. This enabled a vital opportunity for those living with and beyond cancer to speak with others during a year many felt disconnected.



*Many thanks to you and everyone at Jo's for this week's Let's Meet. I've really enjoyed seeing friendly faces and learning how to come out the other side of a diagnosis with a smile.*

We were able to expand our reach further with additional virtual events, including on social media. Sessions covered topics including PRD and lymphoedema, and were pleased to work with partners such as The Vagina Museum and Royal College of Obstetricians and Gynaecologists (RCOG).



*Thank so much. I've been driving myself crazy with anxiety. Automatically going to reoccurrence and driving myself crackers in the process and further driving the health-related anxiety. I really needed to hear this today.*





## Getting the facts out

**Despite the challenges of COVID, we were able to re-focus our funding priorities to launch projects where the need was greatest. Highlights include:**

- Co-produced online cervical screening resources to support trans men and / or non-binary people wanting to attend screening. This was in partnership with LGBT Foundation, following research lead by Dr Alison Berner, which found only half of those eligible have attended screening. The research was published in the British Journal of General Practice and our piece on BBC News Online enabled us to reach a wide audience. We have had over 5,500 views of these resources and the work led to a roundtable with the All Party Parliamentary Group on Global LGBT Rights discussing changes to health policy and practice to better support this group
- A new patient resource on LLETZ, in partnership with RCOG, following findings from our own research that a large number of those affected felt uninformed about the procedure and unprepared for side effects. This publication has been downloaded 300 times and has been viewed more than 18,000 times since launch
- Working with cancer alliances, including RM Partners and North East London Cancer Alliance, to deliver training focusing on non-clinical staff
- Collaborating with the World Health Organization, Cancer Research UK and the Eve Appeal to support the launch of the first global call to action to eliminate cervical cancer

In January, Cervical Cancer Prevention Week fell when many GP surgeries were struggling to provide screening, and many patients were unsure whether it was safe to attend. We encouraged sharing of tips and supportive messaging around screening. Our key message, in response to increased anxiety, was 'be kind'. We took the opportunity to amplify our calls for faster action on HPV self-sampling, releasing research which found over 60% would prefer to self test.

We had widespread media coverage including Sky, ITV and Forbes. Alex Davies Jones, the MP for Pontypridd, shared her story of treatment for cell changes with us, leading to pieces on Woman's Hour and BBC Online.

Celebrities including Ellie Taylor, Laura Tobin, Sunetra Sarker and Katie McGlynn joined the campaign helping spread our messages far and wide, leading to #CervicalCancerPreventionWeek

trending on Twitter and over 17,000 accessing a bespoke Instagram filter.

In response to the surge in services users coming to us with questions and concerns about HPV, we chose this as our focus for June's Cervical Screening Awareness Week. Our activity led to a 60% increase in web traffic and with 97,000 users coming to us over the week to get trusted information and facts about the common virus.

Thanks to funding from the Scottish Government, we were able to run one of our largest advertising campaigns to date starting in June. The move to HPV primary screening coincided with COVID lockdowns and we took the opportunity to share messages about what it means and what to expect. Thousands scanned a QR code on adverts in the media and on highstreets to find out more about HPV primary screening on our website.

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## Zoe

I was diagnosed with CIN3 cells and HPV during COVID. I had no idea what either meant but thankfully found Jo's. If I hadn't had the Jo's Forum I don't know what I'd have done. I had treatment for my cell changes but was called in to discuss my results and the Forum was a lifeline at that point as I was so scared. I searched for success rates, why I would be invited in and I think I actually knew what was going to be said so I almost wasn't surprised when I was diagnosed with cervical cancer. I opted to not have a hysterectomy as we really want a second child but that was not an easy decision to make. The cancer was removed, but the abnormal cells are still there unfortunately and the next steps are being discussed. I think the aftermath is harder than the actual diagnosis, it was so fast.

I'll have to have a biopsy to see what's happening and I have everything crossed we can have a chance at a second baby.

That screening appointment could have saved my life. It has given me opportunities to still be in some sort of control with future decisions regarding fertility, there are so many amazing things that can be done nowadays.

The Forums are such a lifeline, they mean I can see my own story in others so I know other people have done just that. They give me hope.



# Speaking up for our community

**We worked hard to raise the needs of the community and show those affected they weren't alone.**



Thank you to everyone who shared their story with us during the year. We were able to put a face to the devastating disruption to cancer services by sharing the experiences of those living with cancer, or facing delays and cancellations to test and treatments.

We secured over 1,700 media pieces highlighting our concerns throughout the pandemic, including backlogs in cervical screening appointments and interruptions to the HPV vaccination programme.

HPV remains a constant theme through our communications, working to tackle harmful myths and stigmas. We were pleased to work with Scarlett Moffat, who share her experience of a HPV diagnosis on Loose Women, and Jess Phillips MP who shared hers with the BBC. Both pieces started conversation and helped us direct those who needed it to facts and support.

To all who met with us, listened to our concerns and advocated on our behalf, we thank you. This includes politicians such as Tonia Antoniazzi, chair of the All Party Parliamentary Group on Cancer, who tabled questions, read statements, and the hundreds who joined Cervical Cancer Prevention Week encouraging constituents not to delay attending.

Our work was mentioned in Parliament on many occasions, including an oral question from Nickie

Aiken MP which gained the following response from Jacob Rees-Mogg MP:

“I know that many are worried about whether it is safe to attend their screening appointment. Many precautionary measures have been put in place, and everyone receiving an invitation for an appointment should attend. Jo's Cervical Cancer Trust has been doing very good work to help communicate this.”

The Scottish and Welsh elections gave opportunities for us to discuss our vision for the future with politicians from different parties, share a manifesto of our hopes for each nation, and ask for their support to reduce the impact of cervical cancer.

We contributed to consultations including England's first Women's Health Strategy, enabling us to advocate for faster adoption of HPV self sampling and greater support for those diagnosed with cell changes following screening

The collective cancer voice grew during the pandemic and we value our relationship with other cancer charities and professionals through coalitions including the One Cancer Voice group, Welsh Cancer Alliance and Scottish Cancer Coalition. Together we are stronger.

# Jaelle

I was googling how to get support and luckily I found the Jo's Helpline. I called to ask what was on offer and I was pointed towards the 1:1 service, which sounded like what I needed.

I had support from my friends and family so I didn't feel alone, but nobody knew what I was going through. No one else could talk to me about how the future would look, what treatment would be like, which symptoms to worry about, the ways I felt. Every time I spoke about the sadness I felt, I was met with people telling me to 'be positive'. My 1:1 sessions, and the Jo's Forum were spaces where I was told that my feelings were normal. I could vent, I could get tips from others. I got productive help rather than just positivity.

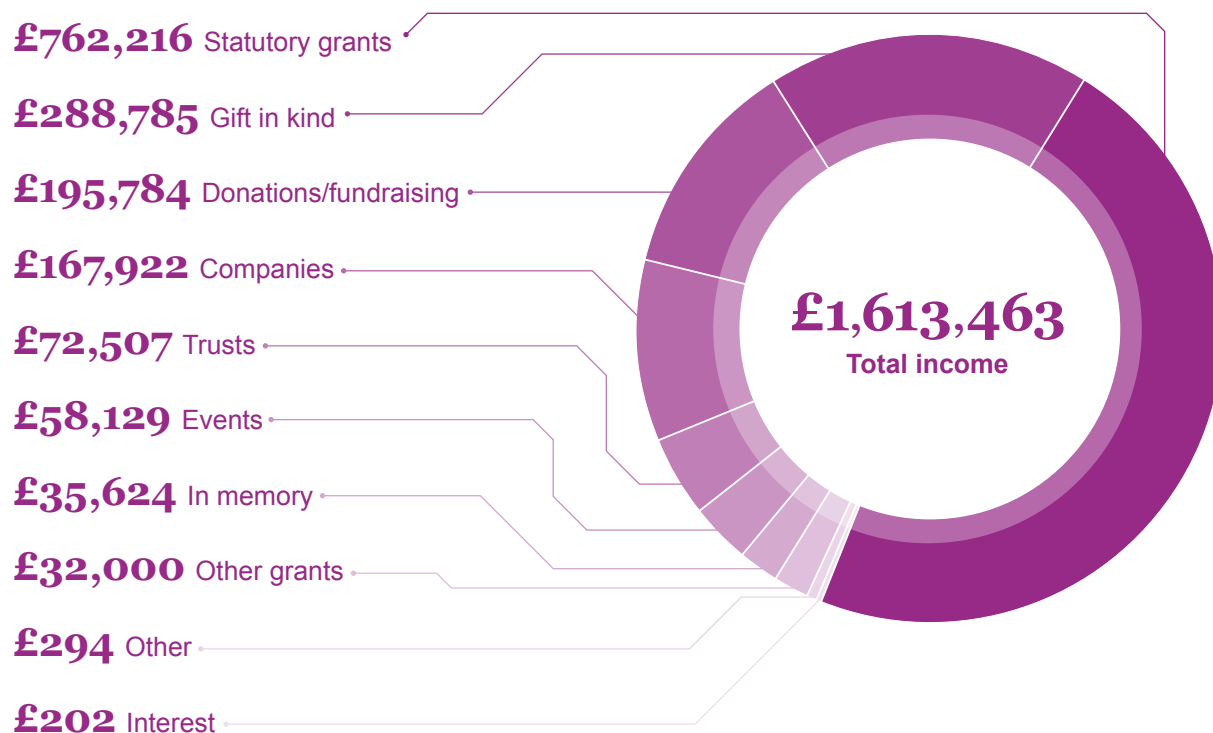
There were certain things my husband could help to do, but often the insurance company only wanted to speak with me. My mental capacity was just not there. Hannah, on the 1:1 service, helped me, and we would talk through a plan of action. I could put my thoughts in the space we created, hear them, organise them and get things sorted out. It was like a diary or an idea bank.

The service was very personal. With all the hardships I went through, I felt that Hannah was interested and invested in my journey. She was actually so excited when I finally got in for treatment, and we celebrated together! I look forward to telling her when the plans we put in place together work out, and it's so nice to celebrate little milestones with someone who gets it. I am glad I found the 1:1 service when I did, at the beginning of my journey. It meant that I knew what was coming and what to expect. Mental health is so important on this journey. I have tried to stay positive, but on the days that I wasn't OK, I really needed the help I got from Hannah. Managing your emotions helps you manage. Even if you don't think you need the support, you will get more out of the service than you think.

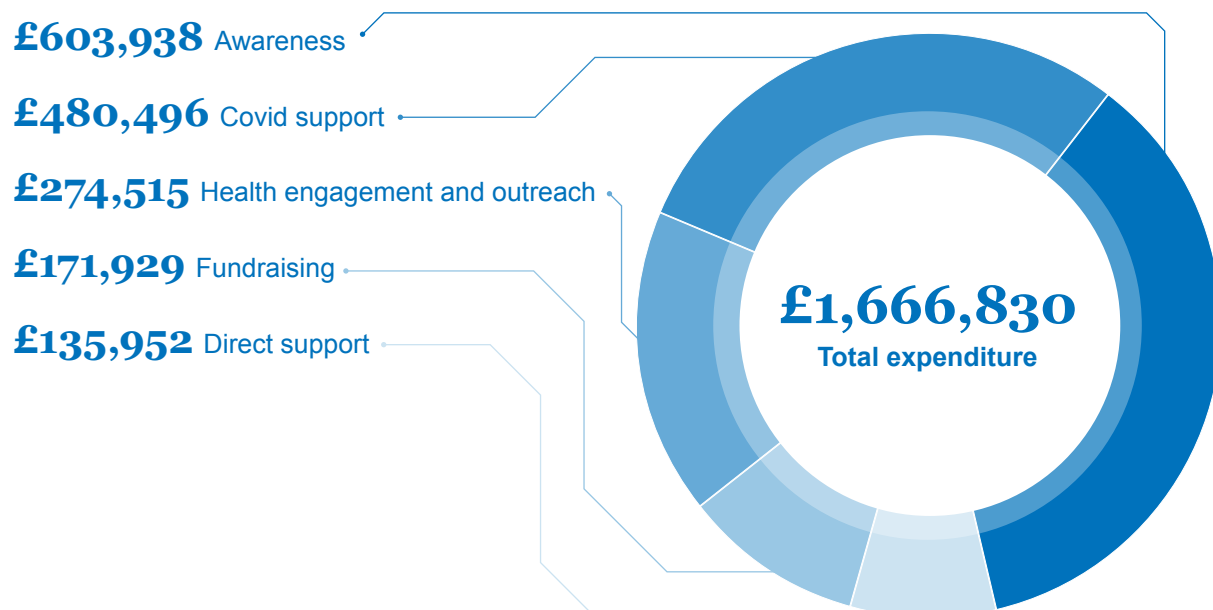


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# Income 2020-21



# Expenditure 2020-21





**Contact us:**

**Jo's Cervical Cancer Trust**

📍 CAN Mezzanine,  
7-14 Great Dover Street  
London, SE1 4YR

T 020 3096 8100

W [jostrust.org.uk](http://jostrust.org.uk)

E [info@jostrust.org.uk](mailto:info@jostrust.org.uk)

🐦 @JoTrust

📘 Jo's Cervical Cancer Trust

📷 [joscervicalcancertrust](https://www.instagram.com/joscervicalcancertrust)

**Call our Helpline:**

**0808 802 8000**

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