

# Jo's Cervical Cancer Trust

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## What's your mission?

Every day in the UK three women die from cervical cancer with another eight diagnosed and facing an uncertain future. In addition around 300 000 women a year are told they have an abnormality that might require treatment. Jo's Cervical Cancer Trust (<http://www.jostrust.org.uk>) is the UK's only charity dedicated to those affected by cervical cancer and cervical abnormalities. We are a national charity and our head office is in London, UK; we have four full-time members of staff.

## What originally happened to create a need for this organisation?

The charity was set up by James Maxwell in memory of his wife Jo, who died from cervical cancer at the age of 40 years. Following Jo's diagnosis she (and James) had difficulty finding good information about every aspect of cervical cancer. It was their hope that one day everyone would have easy access to the best and most up-to-date information and medical advice. Most importantly for Jo, it was her wish that women affected by cervical cancer would have the opportunity to communicate with others facing similar challenges. These wishes remain central to the charity's vision today.

## Describe a typical client/user

Our target audience includes women eligible for cervical screening, those affected by cervical cancer or related abnormalities (including families and friends), hard-to-reach communities such as black and minority ethnic groups and lesbian women, girls eligible for the human papillomavirus (HPV) vaccine, and of course health professionals (primary and secondary).

## What is the service you offer?

We provide information and support online and face-to-face, including a dedicated website with information written and reviewed by experts, a wide range of factsheets and materials, and an online

forum where women can share experiences. We also provide a facility whereby women can send questions to a panel of medical experts, we have a dedicated helpline (Tel: 0808 802 8000) throughout the UK, and we also hold local support groups.

## Do you run any special events?

We campaign throughout the year. For example, in 2011 we ran events at all UK parliaments to ensure policymakers are aware of the key issues related to cervical cancer, and every year we run 'Let's Meet', our annual information day for women affected by cervical cancer. This offers an opportunity to connect with others affected, learn more about issues related to cervical cancer and share experiences.

## How do you see yourself fitting with (or competing with) other similar organisations in the field?

While we are the UK's only charity focusing on cervical cancer, we work and partner with other charities such as Breast Cancer Care, Ovarian Cancer Action, Ethnic Minority Cancer Awareness Week, Target Ovarian Cancer, Ovacom, Macmillan and Bowel Cancer UK.

## How do you get clients?

Clients come to us in many ways, including referrals from health care professionals, recommendations from friends, family and other charities, the web and posters and other advertising campaigns.

## Where do you advertise?

Our advertising is varied – for example, we often run stands at specialist health care events – but we also use 'real life' stories in targeted magazines and promote the charity in cinemas, bars, health clubs and even shopping centres or motorway service stations. Thanks to a grant from Google, we are using their advertising to ensure people reach us through the web. We also underwent a major rebranding exercise in 2010 that has seen a significant

increase in awareness of the charity and the number of people we educate and support.

### What are the top three problems clients present?

First, clients often come to us with some anxiety around screening results. Second, they may not even understand what cervical screening is, and finally we also get women diagnosed with cervical cancer wanting support.

### What's been your biggest triumph over the years?

Our biggest triumph so far has been our key role in campaigning for the implementation of the HPV vaccination that can prevent 70% of all cervical cancers. This has led to the introduction of new face-to-face services that increase the support we offer across the UK: these services are manned by those suffering from cervical abnormalities or cervical cancer, or by health professionals in the field.

### What's been your biggest problem?

Despite the fact that cervical cancer is largely preventable, awareness of the disease is generally low. Women need to be better educated about how they can take proactive steps to reduce their risk of getting it.

### What's your biggest worry for your organisation?

Although cervical cancer is preventable, as an organisation we are concerned that the number of women screened is falling. Over one in five women did not attend for screening last year, and as coverage falls we are likely to see cases of cervical cancer rise. Particularly worrying is the statistic that over 37% of women aged 25–29 years have not been tested for more than 3 years and we are now seeing a drop in uptake in those aged 50+.

Our other concern is financial. Although the last 3 years have been positive in raising funds, the current

### FURTHER INFORMATION

**Who:** Jo's Cervical Cancer Trust  
**Where:** 16 Lincoln's Inn Fields, London WC2A 3ED, UK  
**Helpline:** 0808 802 8000  
**E-mail:** info@jostrust.org.uk  
**Website:** www.jostrust.org.uk

economic climate makes it likely to be more challenging and this may impact on the speed we can expand and provide support services across the UK.

### What are your most exciting plans/biggest hopes for the future?

Our hope is that thanks to the HPV vaccination, and by persuading more women to attend cervical screening, we could see a significant reduction in incidence and death from cervical cancer.

We are looking to train significantly more volunteers to work on our services, enabling us to reach and support many more women affected by cervical cancer or cervical abnormalities and expand our reach across the UK.

Our income has tripled over the last 3 years; this means we can increase our reach/support and develop our education programmes. We are looking for continued growth to expand all areas of our work.

**Competing interests** None.

**Provenance and peer review** Commissioned; internally peer reviewed.

**Editor's note** This article is one in a series of occasional articles on key health organisations worldwide. The Journal would be pleased to hear from other organisations, particularly those based outside the UK, which would like to be similarly profiled.

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The section can be accessed from the front page 'Home' and under the sub-menu 'Courses & Meetings'.