**Embargoed until: 00.00 Thursday 19th October 2017**

**Ovarian cancer charity report reveals gaps in cancer prevention**

**A report published by charity Ovarian Cancer Action has found the NHS is still missing the opportunity to use BRCA testing as an effective cancer prevention strategy, and women are dying as a result.**

* 29% of women diagnosed with ovarian cancer are not being offered BRCA testing
* 71% of people have not heard of BRCA gene mutation
* 33% of respondents received no counselling before making a decision on genetic testing
* 42% received no counselling or support after their genetic test results

The report revealed that despite Government guidelines, 29% of women diagnosed with ovarian cancer are not being offered BRCA testing and yet this is likely one of the best tools to identify carriers.

BRCA gene mutation carriers have an increased risk of ovarian, breast, pancreatic and prostate cancers. Around 15% of cases of ovarian cancer are linked to BRCA - this equates to over 1,000 women a year whose lives could potentially be saved1 and yet, 71% of people have not heard of the BRCA gene2.

Those who carry the faulty gene have a 50% chance of passing it on to their children and if undiscovered, consequences can be devastating.

Rosie Lapsley unknowingly inherited the BRCA1 gene mutation from her mum, who died of breast cancer. Encouraged to look into her family history, she discovered her aunt died of ovarian cancer. At the time, this wasn’t enough for Rosie to qualify for genetic testing, until her younger sister wasdiagnosed with fallopian tube cancer and found to carry the faulty gene. The family underwent testing and revealed Rosie’s mum had passed down the gene mutation to four out of her five children. Another of Rosie’s sisters was diagnosed with fallopian tube cancer and then Rosie was diagnosed with aggressive ovarian cancer.

Rosie said: “My treatment was not pleasant but I have recovered well. My two sisters have had significant health issues as a result of chemotherapy. My children were offered genetic testing; thankfully my son did not have the mutation but my daughter does. If only I had known about testing, then my family and I would have been saved so much pain and heartache and the NHS would have been saved a small fortune in treatment costs. Thankfully the next generation will all have the advantage of genetic testing and advice.”

Ensuring women receive genetic counselling before and after their BRCA test is imperative, as test results can have far reaching emotional implications for the individual and their family. Worryingly, Ovarian Cancer Action found 33% of respondents received no counselling before genetic testing and 42% received no counselling or support after. Risk-reducing surgeries will decrease a carrier’s risk of ovarian cancer but could affect fertility and cause premature menopause.

**Katherine Taylor, Chief Executive of Ovarian Cancer Action, said:** “Every eligible woman who has been denied testing and goes on to develop ovarian cancer represents a cancer prevention failure. Treatment for ovarian cancer lags behind other, better known, cancers and survival rates remain low. BRCA testing is one of our strongest weapons in the fight against this disease.

“It is unbelievably important for eligible men and women to have access to testing and that they receive support in making the right decisions for themselves and their families. At Ovarian Cancer Action we’re on a mission to stop women dying before their time and we’ll continue to take action on BRCA testing until it fulfils its potential to save thousands of lives.”

**ENDS**

**Notes to Editor**

**To request a copy of the full report ‘Acting on BRCA: Breaking down barriers to save lives’ email** **Tori@ovarian.org.uk** **or call 020 7380 1730**

All stats are from the Acting on BRCA: Breaking down barriers to save lives’ report unless otherwise cited.

1 Source: CRUK [cancerresearchuk.org/health-professional/cancerstatistics/statistics-by-cancer-type/ovarian-cancer](http://www.cancerresearchuk.org/health-professional/cancerstatistics/statistics-by-cancer-type/ovarian-cancer)

2 Source: ‘Public attitudestowards BRCA’ survey conducted by Populus on behalf of Ovarian Cancer Action

*What does BRCA stand for?*

BRCA is an abbreviation for “BReast CAncer”. BRCA1 and BRCA2 are genetic mutations that increase a carrier’s chances of breast, ovarian, prostate and pancreatic cancers. The increased risk breast cancer risk was discovered by scientists first, hence the abbreviation.

*What is a BRCA gene mutation?*
Every individual has the BRCA1 and BRCA2 genes, and we inherit two copies, one from each of our parents. They are called tumour suppressor genes, and their job is to repair damage in cells and prevent them from growing and dividing too rapidly. Mutations in these genes can cause cells to become abnormal and grow in an uncontrolled way and increase a risk of both breast and ovarian cancer, as well as other cancers.

The table below shows estimated cancer risk by age 70.

**Estimated Lifetime Cancer Risk (up to age 70)**

|  |  |  |  |
| --- | --- | --- | --- |
| **Type of cancer** | **General population** | **BRCA1** | **BRCA2** |
| Ovarian cancer | 2% | 40-60% | 10-30% |
| Breast cancer in women | 11% | 60-90% | 45-85% |
| Breast cancer in men | 0.1% | 0.1-1% | 5-10% |
| Prostate cancer | 12% | ~10% similar to normal population | 20-25 % |
| Pancreatic cancer | 1.40% | ~3% | ~5 |

Source:The Royal Marsden NHS Foundation Trust

A beginner’s guide to *BRCA1* and *BRCA2*, The Royal Marsden NHS Foundation Trust, <https://www.royalmarsden.nhs.uk/sites/default/files/files_trust/beginners-guide-to-brca1-and-brca2.PDF>