

100 million women in the prime of their lives have endometriosis

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The World Endometriosis Research Foundation (WERF) and the European Society of Human Reproduction and Embryology (ESHRE) are proud to announce the first ever prospective study to assess the hidden cost of endometriosis to society and to women with the disease.

13 centres in ten countries kick-off the EndoCost study today with a goal to identify areas which can be addressed for improvement and subsequent reduction in cost from a very prevalent - yet largely unknown - disease, which affects women during the prime of their lives.

Endometriosis affects an estimated 1 in 10 women during their reproductive years. An average diagnostic delay of up to 12 years, coupled with "hit and miss" treatments, has put an estimated cost to society in the United States alone at \$22 billion a year - higher than the cost of migraine and Crohn's disease. There are no comparable data - yet - in Europe, which WERF and ESHRE now seek to address.

Endometriosis is the biggest cause of <u>infertility</u> and chronic <u>pelvic pain</u> in women. All treatments have side effects and there is no known cure. Yet, there is a lack of government funding given to research into a cure - or even a long term treatment.

28-year old Lisa Gellert has suffered from endometriosis for nine years. "I have seen numerous doctors, and finally had surgery - where none of the disease was removed. Despite having supposedly had 'treatment' I still live in pain and take several days off every month because I am



incapacitated", said Gellert.

WERF chief executive, Lone Hummelshoj worries what mismanagement such as Gellert's is costing national healthcare systems. But, it is not about healthcare systems alone according to Hummelshoj: "A large proportion of women with endometriosis have to take time off work every month either due to severe symptoms, or because of doctors' appointments and treatment regimes. This has a profound effect on society, but most certainly also on the women themselves, whose personal cost - both financially and emotionally - is substantial. The effect on relationships, not least when fertility becomes an issue, must not be under-estimated either! The EndoCost study will be the first ever to investigate this direct and indirect cost, at a societal and personal level. We hope the results will spur national governments on to take endometriosis seriously and invest in research to prevent the next generation of women having to suffer during the prime of their lives the way this generation has", said Hummelshoj.

Results from the EndoCost study are expected to be published during the second quarter of 2010.

More information: See also: www.endometriosisfoundation.org/endocost.php

Source: European Society for Human Reproduction and Embryology

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