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**100 million women in the prime of their lives have endometriosis  
which has a higher socio-economic impact than migraine and Crohn's disease  
-- New study to assess societal costs commences today! --**

The World Endometriosis Research Foundation (WERF) has raised sufficient funds to commence 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 now seeks to address.

Endometriosis is the biggest cause of infertility and chronic pelvic pain 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 mis-management 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.

See also: <http://www.endometriosisfoundation.org/endocost.php>

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## NOTES TO EDITORS:

**Endometriosis** is a condition where tissue, similar to the lining of the uterus, is found in other areas of the body. This tissue responds to a woman’s hormonal cycle and develops into nodules, lesions, cysts in the ovaries, and adhesions, resulting in inflammation, pain and infertility. Treatments include painkillers, hormonal treatments (often with brutal side effects), surgery, and hysterectomy. None of these treatments guarantee relief, and there is no known cure ([www.endometriosisfoundation.org/endometriosis.php](http://www.endometriosisfoundation.org/endometriosis.php))

Endometriosis is predominantly found in women of reproductive age from all ethnic and social groups, and the consequence of the disease has a major impact on quality of life for the estimated 100 million sufferers worldwide.

**The World Endometriosis Research Foundation (WERF)** was created in 2006 as the first global charity to foster research in endometriosis to improve knowledge and treatments. Its vision is a day when no woman is crippled by endometriosis nor prevented by the disease from having children. To achieve this WERF carries out well powered, international multi-centre trials, and support specific research projects investigating disease mechanisms. EndoCost is WERF’s third project, and the charity is now working with 32 centres in 20 countries ([www.endometriosisfoundation.org](http://www.endometriosisfoundation.org))

**The EndoCost consortium consists of:** Leuven University (Belgium) which coordinates the study; Glostrup Hospital (Denmark); CHU de Clermont Ferrand (France); KEZ-Berlin (Germany); Medizinische Hochschule Hannover (Germany); Semelweiss University (Hungary); University of Milano (Italy); University of Bern (Switzerland); University of Edinburgh (United Kingdom); Christus St Frances Cabrini Hospital (USA); The Cleveland Clinic (USA); University of Wisconsin-Madison (USA); University of Maastricht (The Netherlands).

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