Achievements 2006 - 2013

The World Endometriosis Research Foundation (WERF) was established on 11 July 2006 as a registered company in England and Wales (#5872316), and was registered on 14 November 2006 with the English Charity Commission (#1116775). Status as a 501(c)3 organisation in the USA has been granted in the state of California and Federal exemption is pending.

Support for core funding has been provided by the American Society for Reproductive Medicine, the European Society of Human Reproduction and Embryology, and the World Endometriosis Society.

MISSION

WERF fosters research into endometriosis to improve knowledge and treatment(s) by providing a platform that:

1. facilitates and carries out well-powered international multi-centre studies involving sufficient patient numbers to provide results of statistical significance, and
2. supports specific research projects investigating disease mechanisms.

This enables global collaboration amongst researchers to ensure that:

- collaborative research is carried out between international centres;
- strict protocols are enforced to ensure research is of high quality
- datasets are shared;
- encouraging results lead to further research

so that results can be translated into viable treatments to provide a solution for those affected by endometriosis.

WERF’s vision and goal is a day where no woman’s life is compromised by endometriosis and she is not prevented from having children due to the disease.

WERF is currently working with 45 centres/organisations in 21 countries on six continents.

ACHIEVEMENTS

Since 2007 WERF has raised €667,841 (~$844,000) to carry out three international studies investigating the impact, cost, and predictability of endometriosis:

Global Study of Women’s Health (GSWH)

GSWH is the first prospective epidemiological study to investigate the impact of and risk factors for endometriosis in ten countries on five continents (16 centres) involving 1,418 women - a study of this scale had never been undertaken before.

Principal investigator: Dr Krina Zondervan, Oxford University
Study coordinator: Dr Kelechi Nnoaham, Oxford University
Achievements 2006 - 2013

Publications:
• The protocol was published in January 2009 (Nnoaham et al, J of Endometriosis 2009;1:36-45);
• The main manuscript was published in July 2011 (Nnoaham et al, Fertil Steril 2011;96(2):366-73), and was subsequently chosen by Fertil Steril as their first multi-media interview on their website featuring Kelechi Nnoaham and Lone Hummelshoj.

Manuscripts under preparation:
• Relationship between endometriosis an alcohol consumption (Rosanna Bevan, medical student);
• Symptom-diagnosis interval along the covariates of nationality, ethnicity, and age (Drs Emma Doubal and Andrew Horne, University of Edinburgh);
• Effect of empirical use of contraceptives on the pain and quality of life (Drs Andreas Stavroulis and Ertan Saridogan, University College London);
• Association between naevi and endometriosis (Dr Mathi Arasu, Oxford University) – together with WHSS data.

Presentations:
• Preliminary findings were presented (invited) at FIGO 2009 by Kelechi Nnoaham and Lone Hummelshoj;
• Abstract on main findings was accepted for presentation at ESHRE 2010 by Kelechi Nnoaham, and singled out for one of the ESHRE press conferences;
• Abstract on the relationship between endometriosis and alcohol consumption was accepted for presentation in a main seminar at the 11th World Congress on Endometriosis in 2011 presented by Rosanna Bevan;
• Lone Hummelshoj has presented main findings of the GSWH data at numerous meetings between 2009 and 2011 (invited), and addressed 100 female US state legislators in Washington DC on 17 November 2011 on the impact of endometriosis based on the GSWH and EndoCost data;
• Abstract on the effect of empirical use of contraceptives on the pain and quality of life was presented as a poster at ESHRE 2012 by Ertan Saridogan.

In July 2011 Dr Kelechi Nnoaham was awarded his DPhil at Oxford University for his work on GSWH.

Women’s Health Symptoms Study (WHSS)

WHSS is the first prospective epidemiological study to investigate the possibility of developing a predictive model for endometriosis. Such a study had never been undertaken before. WHSS involves 1,396 women from 19 centres in 13 countries on five continents.

Principal investigator: Dr Krina Zondervan, Oxford University
Study coordinator: Dr Kelechi Noaham, Oxford University

Publications:
• The protocol was published in January 2009 (Nnoaham et al, J of Endometriosis 2010;1:36-45);
• The main manuscript was published in May 2012 (Nnoaham et al, Fertil Steril 2012;98(3):692-701).

Presentations:
• Preliminary findings were presented (invited) at FIGO 2009 by Krina Zondervan;
Achievements 2006 - 2013

- Preliminary data was presented (invited) by Krina Zondervan at the 10th International Symposium on GnRH in 2011, and as an invited keynote lecture at the 11th World Congress on Endometriosis in 2011;
- Abstract on clinical symptoms as predictors of a surgical diagnosis of endometriosis was presented at SGI 2011 by Kelechi Nnoaham;
- Abstract on predictive models of endometriosis (towards a screening tool to assess women for surgery) was presented at ASRM 2012 by Kelechi Nnoaham.

**EndoCost**

EndoCost is the first prospective study to investigate the societal and personal cost of endometriosis. A study of this scale, involving 905 women from 12 centres in 10 countries on two continents, had never been undertaken before. The study also incorporates a retrospective element, enabling life-time calculation of costs and long-term impact of endometriosis.

Principal investigator: Dr Steven Simoens, University of Leuven

**Publications:**
- The protocol was published in January 2011 (Simoens et al, Gynecol Obstet Invest 2011;71(3):170-6);
- Main manuscript with prospective cost data was published in May 2012 (Simoens et al, Hum Reprod 2012; 27(5):1292-9);
- Manuscript of the long-term impact of physical, mental, and social well-being of women with endometriosis was published in July 2013 (De Graaff et al, Hum Reprod 2013; ePub).

**Manuscripts under preparation:**
- National data (several co-investigators are preparing publications in their own languages with data from their country).

**Presentations:**
- Abstract on prospective data was presented as a poster at ESHRE 2011 by Thomas D’Hooghe;
- Abstract on retrospective data on quality of life was accepted as an oral presentation at ESHRE in July 2011 by Aisha de Graaff;
- Abstract on retrospective data on sex and quality of life was accepted as a presentation in a main seminar at the 11th World Congress on Endometriosis in 2011 and presented by Aisha de Graaff;
- Prospective cost data have been presented at several meetings in 2011-2012 by Lone Hummelshoj, including a meeting in Washington DC with 100 female US legislators;
- Abstract on retrospective cost data was presented as a poster for ASRM 2012 by Lone Hummelshoj.

**CURRENT PROJECT**

**EPHect**

The Endometriosis Phenome and Biobanking Harmonisation Project (EPHect) is a ground-breaking, global, initiative, which aims to facilitate large-scale cross-centre, longitudinal, epidemiologically robust, biomarker and treatment target discovery research in endometriosis through the development of a consensus on:
Achievements 2006 - 2013

1. Detailed clinical phenotyping (phenome) data to be collected from women with endometriosis and controls to allow collaborative sub-phenotype discovery and validation analyses;

2. Standard Operating Procedures (SOPs) for banking of biological samples from women with endometriosis and controls, with respect to collection, transport, processing, and long-term storage.

€81,000 have been raised for Stage I (1 and 2 above) to be carried out in 2013 with expected submission for publication in 4Q 2013. Stage II (2014) and its budget will be defined in 3Q 2013.

For more information, please see: www.endometriosisfoundation.org/ephect

Principal investigators: Stacey Missmer, Harvard University, and Krina Zondervan, University of Oxford.

FUTURE PROJECTS

WERF is presently finalising protocols and contracts, and exploring funding for two further studies:

EndoART
A prospective three-arm study investigating whether the pregnancy rate after surgical excision of ovarian endometriomas followed by ART is higher than after ART with or without prolonged GnRH-a pre-treatment.

Principal investigator: Professor Thomas D’Hooghe, University of Leuven
Study coordinator: Dr Carla Tomassetti, University of Leuven

DESPAIR (Dyspareunia, Endometriosis & Sexuality Project Associated International Research)
Investigating the impact of dyspareunia on women with endometriosis compared with non-exposed controls with a view to enhance focus on the need to research pain mechanisms in endometriosis.

Principal investigator: Dr Aisha de Graaff, University of Maastricht

BASIC RESEARCH

To achieve its second priority of being able to fund basic research investigating disease mechanisms, WERF is encouraging volunteers to fundraise to establish a “basic research fund” from individual charitable donations, fundraisers, marathons, etc.

£13,162.00 (~$20,000) has been raised by 31 January 2013, and calls for proposals will be issued once the fund is sufficiently large to sustain a project.