

Hluti af þeim reynslusögum sem Samtökum um endómetríósu hafa borist frá félagskonum samtakanna

KONA 1

STANSLAUSAR BLÓÐPRUFUR, EN EFTIR AÐ ÉG SLÓ Í BORDIÐ EFTIR AÐ HAFA FARIÐ MÁNAÐARLEGA ALLT ÁRIÐ 2011 UPP Á BRÁÐAVAKT VEGNA KVIÐVERKJA VIÐ BYRJUN BLÆÐINGA. VAR FARIN AÐ GETA SAGT Á HVADA DEGI ÉG MYNDI FARA Á BRÁÐAVAKTINA..

ÁRIÐ 1987 FÓR ÉG TIL KVENNSJÚKDÓMALÆKNIS ÞVÍ ÉG VAR MEÐ SVO MIKLA TÚRVERKI, FÉKK AÐ HEYRA AÐ ÞAÐ LAGAST VÍÐ FYRSTA BARN (ég er fædd 1971) EN SVO VAR BARA SAGT AÐ ÉG VÆRI EINS OG MAMMA MÍN, FENGI SLÆMA TÚRVERKI. EN PETTA VARÐ EKKI SVONA ÓTRÚLEGA VONT FYRR EN ÁRIÐ 2011..

ÉG HEF NÚ EKKI NEITT SLÆMT AÐ SEGJA NEMA ÞAÐ ER MEÐ ÓLÍKINDUM AÐ FARA ALLTAF Á BRÁÐAMÓTÖKU Á MÁNAÐAR FRESTI, ALLTAF BYRJUN TÍÐAR, MEÐ KVIÐVERKI..OG LÆKNAR SETJA EKKI 1 plús 1. EKKI HEF ÉG VERIÐ FYRSTA KONAN (af ykkar sögum ad dæma) SEM HEFUR KOMIÐ ÞARNA MEÐ SVO MIKLA VERKI AÐ EKKI ER HÆGT AÐ STANDA NÉ SITJA..Í ÖLLUM ÞESSUM FERÐUM KOM ALDREI KVENNSJÚKDÓMALÆKNIR AÐ SKOÐA MIG...ÞAÐ VAR EKKI FYRR EN ÉG VAR ALLTAF FARIN AÐ HRINGJA Í MINN KVENNSJÚKDÓMALÆKNIR OG SEGJA HONUM AÐ ÉG HAFI VERIÐ AÐ KOMA AF BRÁÐAVAKTINNI..AÐ ÉG FÉKK SPEGLUN

FRÁBÆRT AÐ SJÁ AÐ VIÐ HÖFUM SVONA SVIPAÐAR SÖGUR AÐ SEGJA :-)

KONA 2

En frá því að ég byrjaði á blæðingum hef ég verið með svakalegar blæðingar, þá er ég að.tala um skrúfað frá sturtunni og í alla 7 dagana.

Systir mín gat verið með g-strengsbindi, ég hef aldrei getað það.

Eftir að ég átti stelpurnar mína þá versnaði þetta um helming, bæði verkir og lengdin á blæðingunum. Og að lokum gafst ég upp, var þá búin að

prufa hormónasprautur (virkuðu í viku), einhverjar töflur líka og þegar

kvensjúkdómslæknirinn sagði að það síðasta væri bara hormónafylgjan þá

sagði ég nei takk! Þá var ég reyndar búin að eyða yfir tveimur árum þar sem blæðingarnar voru 3 vikur í senn og svo fékk ég nokkra daga þásu

áður en það byrjaði aftur!

Ég byrjaði á pillunni 14 ára og var því ekki með mikla verki en alltaf miklar blæðingar, hætti svo á pillunni ca 32 ára.

En jæja að lokum heimtaði ég að láta taka úr mér legið og það var gert, 36 ára. Þá kom í ljós að ég væri með endómetríósu, læknirinn útskýrði það nú ekkert

sérstaklega en sagði að það hafi verið orsök blæðingana hjá mér.

Ári síðar þurfti ég að fara aftur því þá var ég með blöðrur á eggjastokunum sem læknirinn sagði að væri vegna endómetríósunar.

Þannig er nú mín saga.

KONA 3

Engar eiginlegar rannsóknir, a.m.k. ekkert sem tengdist sjúkdómnum. Eitt skiptið var "kastið

" talið vera "bólgur í eggjaleiðurum" í annað skipti var það greint sem "botnlangakast"...
Yfirleitt gengu "köstin yfir" á 2 sólarhringum.

Í raun má segja að þetta hafi tekið 30 ár í mínu tilfelli, það var ekki fyrr en ég hafði verið skorin upp, vegna legnáms að sjúkdómurinn uppgötvaðist. Skurðlæknirinn (ekki kvensjúkdómalæknir) treysti sér ekki í að ljúka verkinu, "lokaði mér aftur", hafði "aldrei séð aðra eins samgróninga" og tilkynnti mér (nývaknaðri og vankaðri) að ég væri með legslímuflack! Ég hafði aldrei heyrt um það, hvað þá endómetríósu...!

Upphafið var að ég var 11 ára þegar ég fékk mínar fyrstu blæðingar, sem voru reglulegar alveg frá upphafi. Ég var strax með miklar blæðingar og kvalafullar. Þegar ég var á 15.ári kom upp "nýr flötur" þar sem ég var greind með "innvortis gyllinæð" og ristilkrampa. Þetta var meðhöndlað með lyfjum við ristilkrampa frá þeim tíma og reyndar fékk ég róandi töflur (Diazepam) með ristitöflunum. Það var ekki fyrr en mörgum áður seinna sem ég fékk nýjar töflur við ristilkrampanum, sem virkuðu "bara á ristilkrampanum", sem ég áttaði mig á hvers vegna ég var alltaf þreytt og syfjuð. Veturinn sem ég fékk Diazepamið, var ég í Landsprófsbekk og átti mjög erfirt með að HALDA MÉR VAKANDI OG EINBEITA MÉR AÐ NÁMSEFNINU! Enda var ég á róandi lyfjum!

Það var ekki fyrr en árið 1999 sem ég fór í ofanritaðan uppskurð og síðar annan til kvensjúkdómalæknisins Auðólfs Gunnarssonar, sem reyndist alveg samkvæmt því sem mér hafði verið sagt um hann, alveg frábær læknir og með notalegt viðmót. Ástand mitt var verra en búist var við þegar ákveðið var að ég færi í legnmánið, það þurfti einnig að fjarlægja eggjasstokkana. Ég hef verið á hormónalyfjum síðan, fyrst töflum en síðan með plástur.

Líðan mín breyttist strax og hef ég kallað árin frá aðgerðinni/greiningunni "nýtt líf", "frelsi", ég þurfti ekki lengur að taka lyf við ristilkrampanum og hefur almennt liðið mun betur. Mig grunar þó að ég sé hugsanlega með vanvirkan skjaldkirtil, hef reyndar ekki farið til læknis, heldur lesið mig til og sýnist ég hafa ýmis einkenni sem virðast benda til þessa máls. Ég er ekki dugleg að fara til lækna, finnst einhvern vegin og hefur alltaf fundist "ekkert vera að mér" og að ég sé "hrausti". Ég mætti alltaf í skóla og vinnu, þrátt fyrir hörmungarlíðan oft á tíðum. Ég leit þannig á að þetta fylgdi því að vera kona "blæðingar væru ekki sjúkdómur/veikindi".

Á þessum 30 árum sem liðu þangað til ég fékk greininguna, voru örfá skipti sem ég leitaði til lækna vegna vanlíðunar, en fékk aldrei réttu greininguna og var alltaf "jafn nær". Mér tókst að eiga 2 börn "með eðlilegum hætti", annað þegar ég var 21 árs og hitt tæpum 3 árum síðar.

Læknirinn sem skar mig upp í fyrra skiptið og sá hvers kyns var sagði mér að það hafi sjálfsagt bjargað öllu hvað ég var ung þegar ég átti börnin, annars væri ólíklegt að ég hefði getað átt fleiri. Við hjónin reyndum í mörg ár að eiga fleiri börn en þarna virtist "minn kvóti hafa klárast"...

Hvert barn er kraftaverk og má með sannri segja að mín börn hafi svo sannarlega verið það.

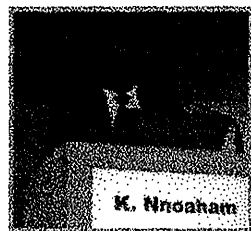
Ég var aðeins 17 ára þegar ég átti að vera með "bólgur í eggjaleiðurum". Ég á frænku sem hafði fengið sömu greiningu, hún er 11 árum eldri en ég og gat aldrei eignast börn. Ég ákvað því strax um tvítugt, komin með maka að láta bara "strax reyna á það hvort ég gæti eignast börn". Ég vissi að það tæki allt svo langan tíma í kerfinu og var þá helst með ættleiðingu í huga. Það var svo upp úr þessu sem farið var að tala um "glasabörn" :

First worldwide study finds women's productivity at work significantly impacted by endometriosis

7 JULY 2011

The first ever worldwide study of the societal impact of endometriosis has found a significant loss of work productivity among women who suffer from the condition – an inflammatory disease associated with chronic pain and infertility during the reproductive years.

Endometriosis accounts for a **significant loss of productivity of 11 hours per woman per week** according to a paper published this week in *Fertility and Sterility* [1].



GSWH Study Coordinator, Dr Kelechi Nnoaham from the University of Oxford, presenting results from the study

The Global Study of Women's Health (GSWH) recruited **1,418 women aged 18-45 from 16 participating centres in 10 countries across five continents**. The women were all scheduled to undergo a laparoscopy to determine whether endometriosis was the cause of their symptoms. Standard methods were used to record the extent of any endometriosis found. Women who had been previously diagnosed with endometriosis were excluded from the study.

The participants were asked to complete a 67-item questionnaire, in their own language, about their symptoms and the impact these had on their lives. The

responses were analysed to compare the impact of symptoms between women with and without a diagnosis of endometriosis.

Study Coordinator, Dr Kelechi Nnoaham, said that the results of this study would help highlight the previously unrecognised plight of an estimated 176 million women around the world whose lives are affected by endometriosis.

Key findings:

- Women with endometriosis experienced an average delay of 7 years from symptom onset until they were finally diagnosed and treated;
- Two-thirds of women sought medical help for their symptoms before the age of 30 (one-fifth below the age of 19);
- 65% of women with endometriosis presented with pain, and one-third of these women were also infertile;
- Infertility alone, without pain, was reported in 14% of women with endometriosis and 29% of those who did not have endometriosis.
- The severity of endometriosis (r-AFS disease stage) did not reflect the severity of a woman's symptoms;
- Women with endometriosis suffer a 38% greater loss of work productivity than those without endometriosis – this difference was mainly explained by a greater severity of pain symptoms among women with endometriosis;

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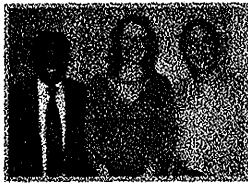
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- Reduced effectiveness at work accounts for more loss of work productivity than time missed from work;
- Non-work related activities, such as housework, exercising, studying, shopping and childcare were also significantly impaired by the painful symptoms of endometriosis;
- The pain symptoms of endometriosis reduce quality of life, with the impact being mainly on physical, rather than mental, health. As symptoms become more severe, quality of life is further reduced.

First ever prospective study paves the way for a better understanding of endometriosis

"Our research is the **first ever prospective study to be undertaken in the field of endometriosis to assess the impact of the disease**", said principal investigator, Dr Krina Zondervan, epidemiologist and senior scientist at the Wellcome Trust Centre for Human Genetics.



GSWH Study Coordinator Dr Kelechi Nnoaham, Principal Investigator Dr Krina Zondervan, and WERF trustee Professor Stephen Kennedy

"We now have to explore **why endometriosis affects different women in different ways**. And, not only are we now able to build on these findings to look at how a woman's experience of the diagnostic and treatment process can be improved, but the data registries resulting from the GSWH will serve as a repository for ongoing and future studies", said Dr Zondervan.

Professor Stephen Kennedy, a co-author and WERF trustee, added: "**Endometriosis affects women during the prime years of their lives**, a time when they should be finishing education, starting and maintaining a career,

building relationships and perhaps have a family. For these women to have their productivity affected, their quality of life compromised and their chances for starting a family reduced, is something society can no longer afford to ignore. **It is time we see serious investment in preventing this debilitating condition in the next generation of women**", said Professor Kennedy.

Co-authors Kelechi Nnoaham and Lone Hummelshoj speak to Fertility and Sterility about the study: [CLICK HERE](#) to view the film clip

Source

1. Nnoaham et al. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011;96(2):366-373 .

See also

- » [More about WERF's Global Study of Women's Health and participating centres](#)
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WERF EndoCost study shows loss of productivity is higher than direct healthcare costs

WERF EndoCost study shows loss of productivity is higher than direct healthcare costs

19 April 2012



The first ever prospective study of the actual cost of endometriosis shows that loss of productivity, due to pain, is twice that of direct health care costs.

The World Endometriosis Research Foundation's EndoCost study included 909 women with a diagnosis of endometriosis from 12 centres* in ten countries [1].

Over a two-month period these women filled in validated questionnaires in their own language assessing the impact of endometriosis on their lives, including questions on a number of subjects such as health care costs, work loss, and quality of life [2].

A study like this, prospectively investigating the direct and indirect cost of endometriosis, has never been undertaken before, and we now have a much clearer picture of the actual cost of this potentially devastating disease



Professor Steven Simoens, University of Leuven, Belgium

said principal investigator, Professor Steven Simoens. The study was unique in that gynaecologists in each participating centres worked in parallel with health economists in each of the countries to calculate to actual cost of endometriosis.

The cost of endometriosis

The average cost of endometriosis is €9,579 per woman – per year. This breaks down to an average €6,298 lost in work productivity and an average €3,113 for direct health care costs. In other words: the cost of inability to work, due to symptoms, is twice that of the direct health costs!

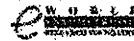
Health care costs were mainly due to:

- surgery (29%)
- monitoring tests (19%)
- hospitalization (18%), and
- physician visits (16%).

It is estimated that 10% of all women of reproductive age have endometriosis [3,4], which would mean that the annual cost of endometriosis in the ten participating countries is estimated as follows:

Country	Number of women	Estimated annual cost
Belgium	~ 250,000	€2.4 billion
Denmark	~ 125,000	€1.2 billion
France	~ 1,400,000	€13.6 billion
Germany	~ 1,860,000	€17.8 billion
Hungary	~ 240,000	€2.3 billion
Italy	~ 1,380,000	€13.2 billion
Netherlands	~ 384,000	€3.7 billion
Switzerland	~ 187,000	€1.8 billion
United Kingdom	~ 1,480,000	€14.2 billion
USA	~ 7,400,000	€70.9 billion

Simoens et al, Hum Reprod 2012



High cost, little investment

The WERF EndoCost study, which was published this month in *Human Reproduction* [1], showed that the cost of endometriosis is similar to that of diabetes, Crohn's disease, and rheumatoid arthritis.

Yet, unlike these other well-known diseases, we see relatively little investment in research into the cause and disease mechanisms in endometriosis



said the Chief Executive of the World Endometriosis Research Foundation, Lone Hummelshoj, who is shocked by how much money is being lost by governments and health care systems who ignore endometriosis.

Lone
Hummelshoj,
Chief Executive,
World
Endometriosis
Research
Foundation

Decreased quality of life was the most important predictor of direct health care and total costs. Costs were greater with increasing severity of endometriosis and the presence of pelvic pain.

Loss of productivity due to the symptoms of endometriosis was also demonstrated in WERF's Global Study of Women's Health (GSWH), published last year in *Fertility and Sterility* [5], showing an average loss of productivity of 11 hours a week in women with endometriosis. Like the WERF EndoCost study, this loss of productivity was driven by pain and a consequent decrease in quality of life.

The World Endometriosis Research Foundation (WERF) works to raise sufficient funds to investigate disease mechanisms to improve treatments for endometriosis so that this vicious cycle can be halted for the next generation of women.

* THE ENDOCOST CONSORTIUM

The EndoCost Consortium comprise: Leuven University (Belgium); Glostrup Hospital (Denmark); CHU de Clermont Ferrand (France); KEZ-Berlin (Germany); Medizinische Hochschule Hannover (Germany); Semelweis University (Hungary); University of Milano (Italy); University of Bern (Switzerland); University of Edinburgh (United Kingdom); The Cleveland Clinic (USA); University of Wisconsin-Madison (USA); University of Maastricht (The Netherlands).

REFERENCES

1. Simoens S, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012 [epub ahead of publication]
2. Simoens S, et al. Endometriosis cost assessment (the EndoCost study): a cost-of-illness study protocol. *Gynecol Obstet Invest* 2011;71(3):170-6
3. Rogers PA, et al. Priorities for endometriosis research: recommendations from an international consensus workshop. *Reprod Sci* 2009;16(4):335-46
4. Adamson GD, et al. Creating solutions in endometriosis: global collaboration through the World Endometriosis Research Foundation. *J of Endometriosis* 2010;2(1):3-6
5. Nnoaham KE, et al. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011;96(2):366-373

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- More about WERF's EndoCost study and participating centres
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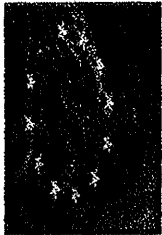
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European Union grants funding for endometriosis work in Europe

10 MAY 2007

Historic funding from the European Union provides encouraging news for millions of women whose lives are affected by endometriosis.



The Public Health Executive Agency of the European Union has to today announced a €296,000 grant to a European coalition of universities and patient support organisations to improve awareness of endometriosis in Europe.

This is the first time that the EU has provided funds for work in the field of endometriosis and is the result of several years of awareness raising in the European Parliament and European Commission by the European Endometriosis Alliance.

Project partners

The partners in this project, which is the first of its kind, are:

- Oxford University (UK)
- Leuven University (Belgium)
- Catholic University of Rome (Italy)
- Hospital San Carlo (Italy)
- Endometriose Foreningen (Denmark)
- Endometriosis UK (UK)
- TNS Social Research (UK)
- Endometriosis.org (Global)

This coalition, bringing physicians, women with endometriosis and professional organisations together, will be working over the next three years to address three main areas of work, beginning with a pan-European quality of life study.

Project aim

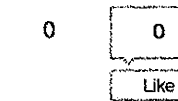
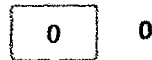
The research aims to engage 10,000 respondents across participating countries in understanding the impact of endometriosis and will also include vital socio-economic data.

The second part of the project will be to create an Internet based Endometriosis Community Gateway which will be the first port of call for anyone wanting information about endometriosis (including the public, health professionals and employers) and guiding them to where they can best find the information they seek.

The final element is the development of a clear strategy for supporting the estimated 16 million women across the EU battling with endometriosis and to strengthen the European Endometriosis Alliance. The grant will enable the European endometriosis charities, many

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Get involved

Help us improve treatments for endometriosis and prevent this disease in the next generation of women. Support the work of the World Endometriosis Research Foundation.

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of whom have very little or no funds, to develop their own work as well as create a more powerful European group.

Rob Music, chief executive of Endometriosis UK, which is the lead partner, says:

“ While there have been some improvements in the diagnosis and funding of endometriosis there is still a long way to go. It is simply unacceptable that millions of women across Europe continue to live with an illness stagnating as a result of misunderstanding and inadequate levels of funding. We are delighted and thankful for the recognition of this need by the EU through this grant which should make a great difference at so many levels.

Lone Hummelshoj, who has campaigned for the past four years for more funding in Europe, expressed her delight at the grant:

“ A lot of work in getting endometriosis officially recognised by the European Union has now paid off. Hopefully, this grant will only be the beginning of serious funding into raising awareness of endometriosis, and to obtain investment for causal research into the disease. Causal research may help develop treatments that actually work, and which subsequently will preserve these women’s fertility, improve quality of life, and reduce socio-economic costs. We are not there yet. But this is an excellent start!

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Italian Health Ministry launches national endometriosis information campaign

18 FEBRUARY 2009

The Italian health ministry has taken its first step to fulfill one of the goals from their five year plan for endometriosis.

Today it launches the first national campaign to raise awareness of endometriosis in collaboration with the Associazione Italiana Endometriosi, which has worked closely with the ministry and senate to make this happen.



WHAT I DON'T KNOW ABOUT MYSELF is a health ministry funded campaign, which includes announcements on TV, radio, and even in cinemas!

After 10 years of hard work, the Associazione Italiana Endometriosi can be extremely proud to be able announce that yet another mile stone has been reached for women with endometriosis in Italy!

We have been lobbying the various governmental departments for a national campaign to raise awareness for years and today for us a dream has come true: the Italian Health Ministry has launched the campaign called, "what I don't know about myself" which raises all those 'not-

talked-about' issues, which may lead to a diagnosis and treatment of endometriosis. This campaign will aid girls and women to become familiar with endometriosis and we hope they will no longer have to endure an average eight year diagnostic delay through lack of knowledge about what is normal and what is not.

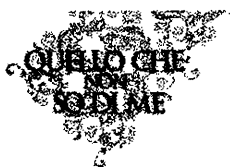
said Jacqueline Veit, President of the AIE.

In addition to TV, radio and cinematic adverts, the health ministry has developed an informative brochure, through which women are encouraged to call a toll free number for more information.

» [Quellochenonsodime Brochure](#)

» [Watch the adverts](#)

» [More information about the campaign](#)



See also

- » [AIE presents a proposal for a new law to the Italian Senate](#)
- » [European Parliament seminar highlights Italian Senate's five year plan for endometriosis](#)
- » [Conclusion of investigation by the Italian Senate into endometriosis as a social disease](#)

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