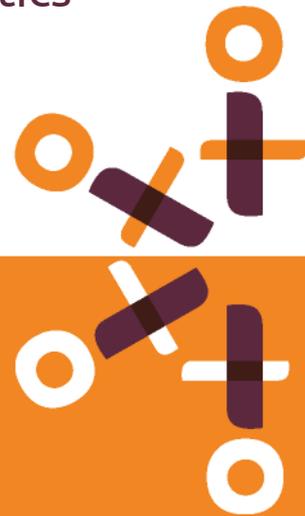


Endometriosis in Ireland

Kathleen King MSc BSc Biomedical Science, Msc Health Informatics

Chairperson EAI



EAI

Founded in 1987 by women with endometriosis to educate, support and further research into endometriosis (and adenomyosis)

Volunteer run

No paid staff

No Government/Regular Funding

No full time volunteers

150 Members

Internationally Recognised

Research Partners

Evidence Based Information

What is endometriosis?

Presence of endometrial like tissue in the pelvis, bowel, bladder, ureter, skin, brain, diaphragm, pericardium, lung

Common, Chronic, Inflammatory Condition

Hormonal influence

Characterised by severe pain - pelvic, back, sexual, leg, chest, abdominal

One of the leading causes of infertility



What is endometriosis?

1 in 10 Women*

155,000 in Ireland

176 Million Worldwide

9 year average delay to diagnosis

Onset of symptoms before 25 yrs old longer delays

Enigmatic disease marred by myths and legends

What is it really like to live with endometriosis?

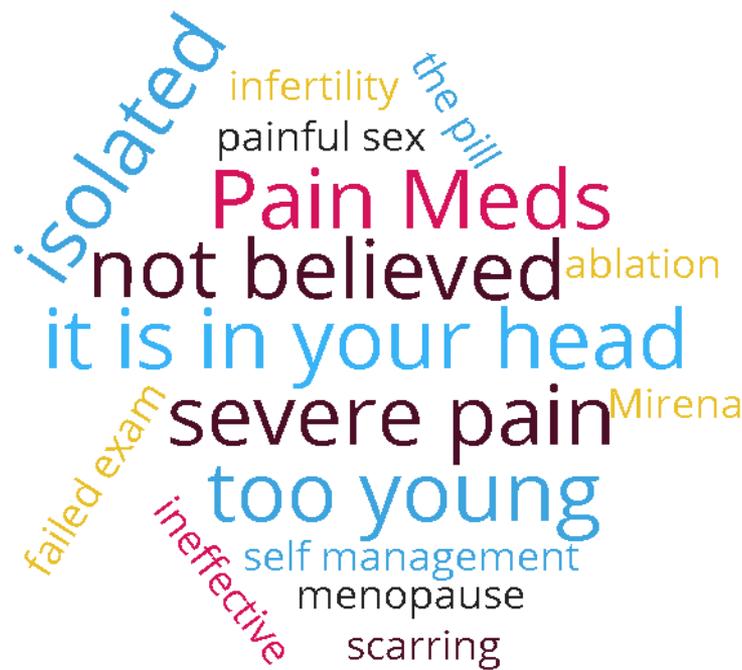


Siobhán

Severe Pain from age 12



What is it really like to live with endometriosis?



What is it really like to live with endometriosis?



Costs Associated With Endometriosis

High levels of absenteeism and presenteeism 6.3 hours per week
16.9% of employee productivity

Recent Australian study living with endometriosis cost AUS\$30,000 a year in direct and indirect costs 6 times greater than those with less severe pelvic pain.

2012, European study put this figure at an average cost of €9,579 per woman – per year.

- €6,298 lost in work productivity
- €3,113 for direct health care costs
- €168 in non healthcare costs

UK Estimates cost of £8.2 billion annually.

Research and Endometriosis

Research funding

NIH (USA) 2014

Diabetes **\$1bn**

Endometriosis **\$7m.**

Spend per individual with Diabetes **\$35.66** Versus Endometriosis
\$0.92.

Australia have recently secured a AUS\$10 million boost for research.

In Ireland, we are currently working with a team at BioInnovate in NUIG as they begin their research into endometriosis

Strength Through Experience

Experience and Knowledge

Trusted worldwide

Part of a worldwide network

Identifiable

Training future advocates

Empowering through education and awareness events

Resource Gaps and Obstacles to Progress

Lack of Dedicated Funds

Lack of Dedicated Time

Human Resources

No Multidisciplinary Centre of Excellence

No recognition of the complexity of endometriosis surgery

No formal access to schools/GPs/Gynaecologists/Health Care Professionals

Funding dries up

Volunteers fall away

Misleading and inaccurate information

Undermined by the lack of support within the medical community

Strategies to Improve Quality of Life

Effective treatment within a reduced time frame - reduces suffering, costs

Work with educational facilities and healthcare professionals

Seek sources of funding to continue work and embark on education programmes

Part of the accreditation process for a Multi Disciplinary Centre of Excellence

Deeper involvement in Irish research

Strengthen international links for research, information and treatment

www.endometriosis.ie

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Learn about endometriosis - symptoms, diagnosis, treatment and support options. Endometriosis affects 176 million worldwide.

Some things about endometriosis to learn and share!

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eai Endometriosis Association of Ireland enabling your everyday

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Fact of the Month

1 in every 10 women in Ireland suffer from endometriosis

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Endometriosis Assoc Ireland
Ireland's only charity representing those living with #Endometriosis. 1 in 10 women 155,000 in #Ireland. (Trans/Cis Males also) Email info@endo.ie linktr.ee/endoireland

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The Endometriosis Association of Ireland gives support & info to those living with and affected by endometriosis and adenomyosis. CRA 20021672 info@endo.ie

Joined February 2010

eai Endometriosis Association of Ireland celebrating 30 years

Tweets 11.2K Following 1,237 Followers 3,790 Likes 8,364

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Helena Tubridy fertility coach, therapist, speaker @FertileExpert · 20h Panel discussion on #endometriosis shared by the wonderful Kathleen King @endo_ireland at The Fertility Forum @FertileForum in @CroisiParkEvents

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