

An Edinburgh team is conducting vital research into how to improve the lives of more than 170 million women globally affected by endometriosis, a debilitating condition that often goes undiagnosed

Hidden suffering

While 80 per cent of adults are familiar with diabetes, fewer than 20 per cent have heard of endometriosis.

That startling figure, provided by Endometriosis.org, emphasises one of the reasons why it is such a difficult condition to research, and why developing better management and treatment remains a challenge.

At least 176 million women of child-bearing age across the world are affected. In the UK, the figure is about 1.5 million, with an estimated 125,000 of them in Scotland, many of them undiagnosed.

Here, Professor Andrew Horne, co-director of EXPPECT (Excellence in Pelvic Pain and Endometriosis Care and Treatment) at the Royal Infirmary of Edinburgh campus, explains how a £100,000 donation from the Charles Wolfson Charitable Trust will support their vital research into the condition, in partnership with NHS Lothian.

What is EXPPECT hoping to achieve?

We want to improve the quality of life for women with chronic pelvic pain and endometriosis by developing novel, personalised treatments.

We formed EXPPECT Edinburgh in 2014 to bring together individuals involved in clinical care with discovery scientists to establish a hub within which new and innovative approaches to treatment can be developed in collaboration with women with endometriosis and commercial partners.

What is the clinical expertise at EXPPECT?

We have a multi-disciplinary team that provides

state-of-the-art, high-quality, evidence-based patient-centred treatment for the management of all grades of endometriosis.

It is one of only two British Society of Gynaecological Endoscopy (BSGE) accredited centres in Scotland.

Why does such a widespread problem struggle to identify funding for research?

Part of the problem is that endometriosis is a “hidden” condition and still has a certain taboo around it.

There remains some gender prejudice, I suspect. Diagnosis and management can be disjointed, leading to sub-optimal treatment.

We are drawing together those different elements so that we have a much fuller and more co-ordinated picture.

You have spoken of “repurposing” existing drugs. What does that mean?

It can take 25 years to bring a new drug to market. What we are doing is identifying novel drug targets to explore possible ways forward by repurposing compounds for other conditions.

We know that endometriosis cells behave in a way similar to cancer cells. It may be that

Right: Andrew Horne and his research team are conducting vital research into endometriosis, part funded by a £100,000 donation from the Charles Wolfson Charitable Trust

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existing cancer drugs, for example, could be modified to treat endometriosis.

We have developed a human tissue/fluid biobank with samples from women with chronic pelvic pain who do or do not have endometriosis. Collecting and archiving samples, according to rigorous protocols, has allowed us to collaborate with other research internationally and to gain new insights into disease related pathology.

We are looking at the repurposing of drugs developed for other indications that we have tested in our specially developed unique preclinical models of endometriosis, as well as fresh approaches based on new insights gained from studies on disease aetiology.

We are working with a range of pharmaceutical companies to increase the range of compounds.

What about funding?

We have managed to secure £10 million in research funding for endometriosis from a range of sources, which is a great show of support for our work and what it can achieve.

Of course, an ongoing research project like this constantly needs more funding, and every grant and donation is hugely important to us.

The £100,000 from the Charles Wolfson Charitable Trust will cover the cost of bringing on

board a research scientist who will be working closely with us to identify potential new drug targets that could lead to a better way of managing the pain and related symptoms – or even cure – for women with endometriosis.

That is crucial work if we are to improve the lives of millions of women across the world.

Visit the MRC Centre for Reproductive Health website at www.ed.ac.uk/centre-reproductive-health

READ MORE

Professor Andrew Home and Carol Pearson's book, *Endometriosis: The Experts' Guide to Treat, Manage and Live Well with your Symptoms*, is available now.

DEBILITATING DISORDER

Endometriosis is a condition where tissue similar to the lining of the uterus (the endometrial stroma and glands, which should only be located inside the uterus) is found elsewhere in the body (endometriosis lesions).

The lesions can be found anywhere in the pelvic cavity: in the ovaries, on the pelvic side-wall, on the bowel or bladder. It can even be found in scar tissue from a caesarean section.

Sufferers can experience debilitating pelvic pain and infertility, leading to time off work or study, low mood and

a breakdown in relationships.

There is no cure as yet. Surgery to remove the endometriosis may bring some relief, but the symptoms often return. Simple pain killers can help, as can hormone treatment, usually in the form of the birth control pill. However, at a time in their lives when younger women are most likely to want to conceive, taking that course of action is not an option.

