

# When menstruation hurts: Learn more about endometriosis <sup>[1]</sup>

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<sup>[2]</sup>



This March is Endometriosis awareness month, a condition that affects more than 50 thousand women in Puerto Rico.

For many women, menstruation is just a nuisance or discomfort. But for one in ten women this process is accompanied by inflammation and pelvic pain so severe that it affects the normal rhythm of their lives. These women are suffering from endometriosis, a condition characterized by **dysmenorrhea** (painful menstruation), **dyspareunia** (pain during intercourse), chronic, disabling pelvic pain, and often **infertility**.

Endometriosis occurs when tissue that normally covers the inner part the uterus (endometrium), moves into the pelvic cavity through the fallopian tubes, and adheres to the organs of the abdominal cavity (ovaries, fallopian tubes, bladder or bowel) forming lesions or ovarian cysts (endometriomas) which are responding to hormonal stimuli of the menstrual cycle, and produce internal micro-bleedings. This in turn activates inflammatory processes, secretion of cytokine and prostaglandin (hormones that make us feel pain), severe pain, and scarring. Over time, this affects the peritoneal and uterine environment and hinders conception.

The lesions of endometriosis use molecular mechanisms similar to cancer, such as adhesion, invasion, creation of new blood vessels (angiogenesis), and protection against cell death by apoptosis. Although endometriosis tissue can invade other organs outside the pelvis, such as the liver, lungs and brain, endometriosis *is not a cancer*.

It is estimated that **one in ten (1 in 10)** women have endometriosis worldwide, which represents **176 million** women affected, of which 40-50% may have problems getting pregnant. In the United States it is estimated that 9.5 million women have endometriosis and in Puerto Rico, a study by the Endometriosis Research Program found that in the island, one in twenty women (**1 in 20**) of reproductive age, or about 50 thousand women have endometriosis. Based on this, it can be estimated that for every woman with endometriosis in Puerto Rico there is one that has not yet been diagnosed. Our study also showed that there is a delay of 8 years on average from the onset of symptoms until the clinical diagnosis is made.

There are several reasons for this **delay in diagnosis**.

- 1) The widespread perception that pain with menstruation is normal.
- 2) There are no specific and sensitive blood tests for the diagnosis of endometriosis. The only way to diagnose it is through a surgical procedure, such as a "**laparoscopy**". During this procedure, a small incision in the abdomen is made and a tube is inserted with a lens through which the gynecologist can see where the endometriosis implants and how severe the condition is.
- 3) Medical plans do not cover the specialized medical care required. For now, endometriosis can only be diagnosed through surgery which must be approved by the plan. Furthermore, lesions of endometriosis have different presentations, and only doctors with a medical expertise can recognize and remove the lesions. Some medical plans place obstacles for obtaining referrals to these specialists, and also to the coverage for the prescriptions that these patients require, some of which are very expensive.

For patients of endometriosis it is extremely important have a diagnosis that explains their symptoms. This helps the patient and provides a framework on which to structure a dialogue with her doctor to establish a plan to treat the condition in the most effective manner, taking into consideration the particularities of each patient. In addition, getting diagnosed provides tranquility to the patient because she knows that there is a cause for symptoms (she's not making it up), and allows her to participate in support groups and educational activities for patients with the same

condition.

### **Is there a cure? What is the treatment?**

Endometriosis has no cure, but there are several treatment strategies that help relieve symptoms. These drugs prevent menstruation, thus preventing bleeding from the lesions and the swelling and pain that accompanies it. Available treatments decrease levels of estrogen (the female hormone) in the body simulating a state of pregnancy or menopause and cause the endometriosis lesions to stop growing and atrophy. In addition, during a laparoscopy, the gynecologist "burns" or removes the visible endometriosis lesions which significantly reduces pain. Usually, the gynecologist will recommend a combination therapy, i.e. laparoscopy followed by six months of hormone treatment, based on the circumstances of each case.

The choice of therapy depends on the severity of symptoms, the location and extent of the lesions, the desire to become pregnant, and age of the patient. Although currently available treatments can have side effects, these can be minimized through the use of hormone replacement therapy and thus help patients complete treatment.

### **What causes endometriosis?**

It is still not clear what causes endometriosis, but genetic, immunological, and environmental factors play an important role in the development of this disease. The genetic theory is based on the observation that women who have a sister with endometriosis have a much higher risk of contracting the disease than women who have no affected relatives. Studies conducted in our laboratory and additional ones worldwide indicate that genetic factors seem to play an important role for some patients.

Our research program has identified inflammatory molecules that are elevated or decreased in the serum of patients compared with women without endometriosis, which could serve as a non-invasive form of diagnosis. One of our most important research projects has helped to obtain evidence that stress can make endometriosis worse. Studies in an animal model of endometriosis determined that psychological stress causes larger lesions and the worse inflammation. Furthermore, these studies showed that stress management and exercise can help arrest lesion growth much and decrease the swelling.

As a result of these studies we can argue that stress management and changes in lifestyle should be part of a comprehensive treatment plan for patients with endometriosis. Finally, research generates knowledge which will allow us to make discoveries that will help us find the best strategies to effectively diagnose and treat this complex disease in the future. But for this we need the participation of voluntary patients to help us generate these data.

The Endometriosis Research Program has partnered with the Puerto Rican Foundation of Patients with Endometriosis. For more information on the efforts of this foundation to support patients with endometriosis and educate society in general of Puerto Rico you can call 787-840-2575 x 2611, 2177, write to [endopr@gmail.com](mailto:endopr@gmail.com) [3], or visit the website [www.endometriosispr.net](http://www.endometriosispr.net) [4] We also invite patients to join our Facebook group, **Endometriosis Puerto Rico**, to learn about our activities throughout the year and this March, as part of the worldwide celebration of Endometriosis Awareness Month. For adolescents, we also have a group on Facebook - **EndoTeens**. Finally, you can follow us on Twitter at **@endopr2010**.

We should never allow anyone suffering from chronic and debilitating pain, which causes disturbances in all facets of her life - work, school, relationships, parenthood - to forego getting help for these symptoms. We must listen and recognize the pain that these women and adolescents feel, and provide a path to diagnosis and treatment, thus avoiding a greater impact on their quality of life.

\*As part of Endometriosis awareness month, Mirada Científica [5] published an interview with Dr. Flores [6], which can be heard here [7]. Dr. Flores is a Professor at the Endometriosis Research Program of the Ponce Health Sciences University - Ponce Research Institute and the Puerto Rican Foundation of Patients with Endometriosis, FPPE, Inc.

For more info on the Endometriosis studies please visit the following links:

Endometriosis and stress

<http://www.ncbi.nlm.nih.gov/pubmed/22527982> [8]

<http://www.ncbi.nlm.nih.gov/pubmed/25015902> [9]

<http://www.ncbi.nlm.nih.gov/pubmed/26900480> [10]

Endometriosis in Puerto Rico

<http://www.ncbi.nlm.nih.gov/pubmed/17976623> [11]

Genetics of endometriosis

<http://www.ncbi.nlm.nih.gov/pubmed/22307873> [12]

<http://www.ncbi.nlm.nih.gov/pubmed/22266326> [13]

<http://www.ncbi.nlm.nih.gov/pubmed/21733505> [14]

### Epigenetics of endometriosis

<http://www.ncbi.nlm.nih.gov/pubmed/25820690> [15]

<http://www.ncbi.nlm.nih.gov/pubmed/23899551> [16]

<http://www.ncbi.nlm.nih.gov/pubmed/22344732> [17]

### Impact of endometriosis

<http://www.ncbi.nlm.nih.gov/pubmed/19926084> [18]

<http://www.ncbi.nlm.nih.gov/pubmed/21621771> [19]

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