

# Endometriosis: What every OBGYN should know

*Tuesday, July 23, 2024*

Lara Harvey, MD MPH

VANDERBILT  UNIVERSITY  
MEDICAL CENTER

- I have no disclosures

# Goals

- Improvements to Knowledge: Learners will understand current research and recommendations on endometriosis as well as social media trends on endometriosis.
- Improvements to Competence (Abilities & Skills): Learners will have more clear perception of information patients are exposed to online regarding this topic as well as
- What will learners be able to do (or do better) after your presentation? Discuss the natural history, diagnosis and treatment options for endometriosis with patients as well as benefits and limitations of information on this topic in the popular sphere.
- Improvements to Medical Practice (Performance): Physicians will counsel patients on options for diagnosis and treatment of endometriosis.
- Improvements to Patient Outcomes: Patients will receive expert guidance in navigating treatment options for endometriosis as well as explanations of material about endometriosis in the popular press and social media.

# Background



Condition in which endometrial glands are found outside the uterus



Gold standard for diagnosis is diagnostic laparoscopy



Average time from symptom onset to diagnosis is 7 years



Treatment is medical (hormonal and anti-inflammatory) and surgical



Affects ~10% of population

M.S. Arruda, C.A. Petta, M.S. Abrão, C.L. Benetti-Pinto, Time elapsed from onset of symptoms to diagnosis of endometriosis in a cohort study of Brazilian women, Human Reproduction, Volume 18, Issue 4, April 2003, Pages 756–759, <https://doi.org/10.1093/humrep/deg136>

# What's new?



Increase in funding and public awareness globally



Shift to considering endometriosis a “whole body” disease



Genetic sequencing studies



Bacteria



New oral therapies



New diagnostics



AAGL Staging system



Social Media

# Movement in the public sector

It's about time

# Public awareness

- Australia
- White House
- In fiscal year for Health Funding
- March is

HOUSE

FAC  
Ar  
Res  
Jill E

Le Monde NEWS INTERNATIONAL VIDEOS ENVIRONMENT FRANCE OPINION FRENCH D

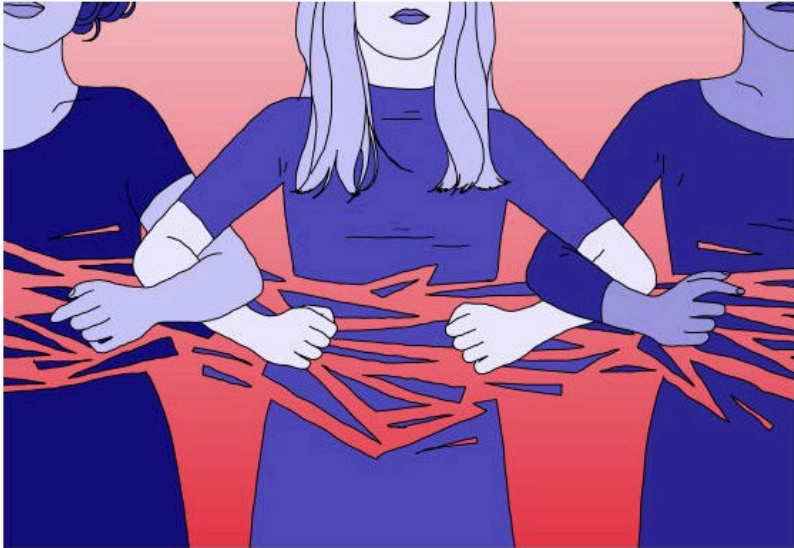
**M CAMPUS** · HEALTH

## Young women use social media to turn endometriosis into a political struggle

For too long, endometriosis has been dismissed by doctors. On social media, a new generation of women is sharing information to help each other, educate themselves and fight against prejudice.

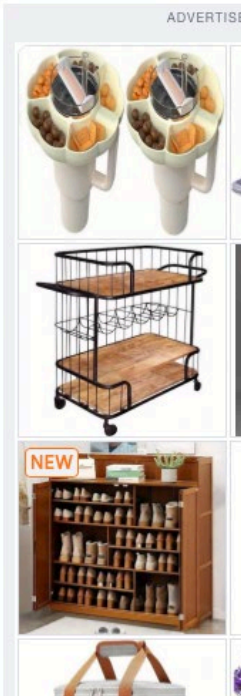
By Léa Iribarnegaray  
Published on June 24, 2022, at 5:22 pm (Paris), updated on June 24, 2022, at 11:14 pm · 6 min read · [Lire en français](#)

Subscribers only



ANNA WANDA GOGUSEY

ADVERTISE



utes  
rs.

# New basic science



# Whole body disease

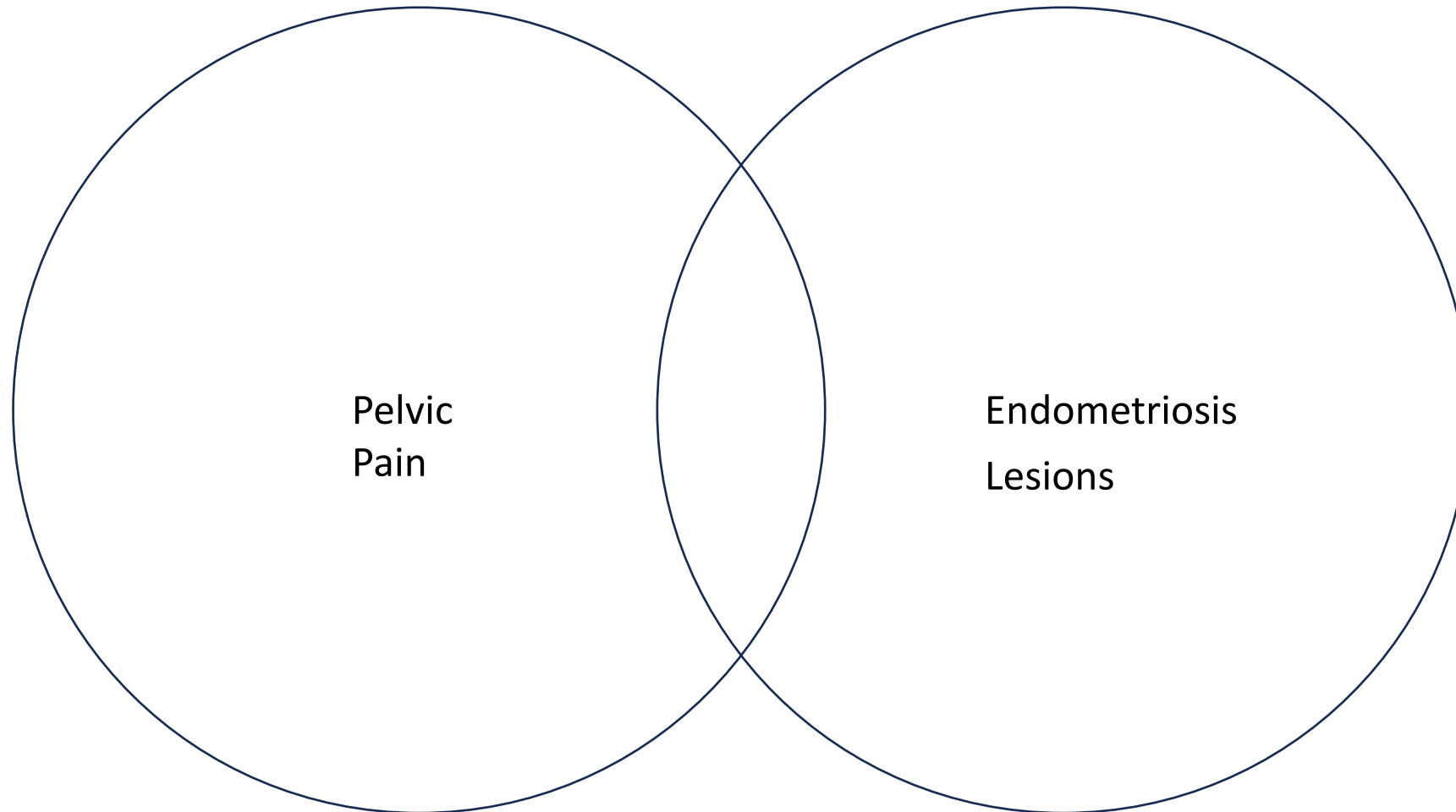
- A Nature genetics study of more than 60,000 individuals with endometriosis and nearly 702,000 without, published in March 2023. Using whole genome analysis, it uncovered a shared genetic basis between endometriosis and chronic pain conditions in regions that control genes associated with pain perception and maintenance.

# Genetic sequencing studies

- May actually be several different diseases
- Genetics studies of patients with ovarian endometriosis versus peritoneal had different genetic patterns.
- Genetics associations for failure of HT and gabapentin have been observed as well.

# Model of endometriosis

---



# Role of bacteria

- June 2023, a study from Nagoya University in Japan noted in a small group of 155 women, 64% of those with endometriosis had members of *Fusobacterium*, a genus of opportunistic, inflammatory bacteria, in their uterine lining compared with just 7% of those without the condition. Also true of the vagina.
- Certain bacteria promote growth of endometriosis lesions in mice
- Variations in gut biome associated with visceral pain in mice

Watson, C. Surge in endometriosis research after decades of underfunding could herald new era for women's health. *Nat Med* **30**, 315–318 (2024). <https://doi.org/10.1038/s41591-024-02795-0>

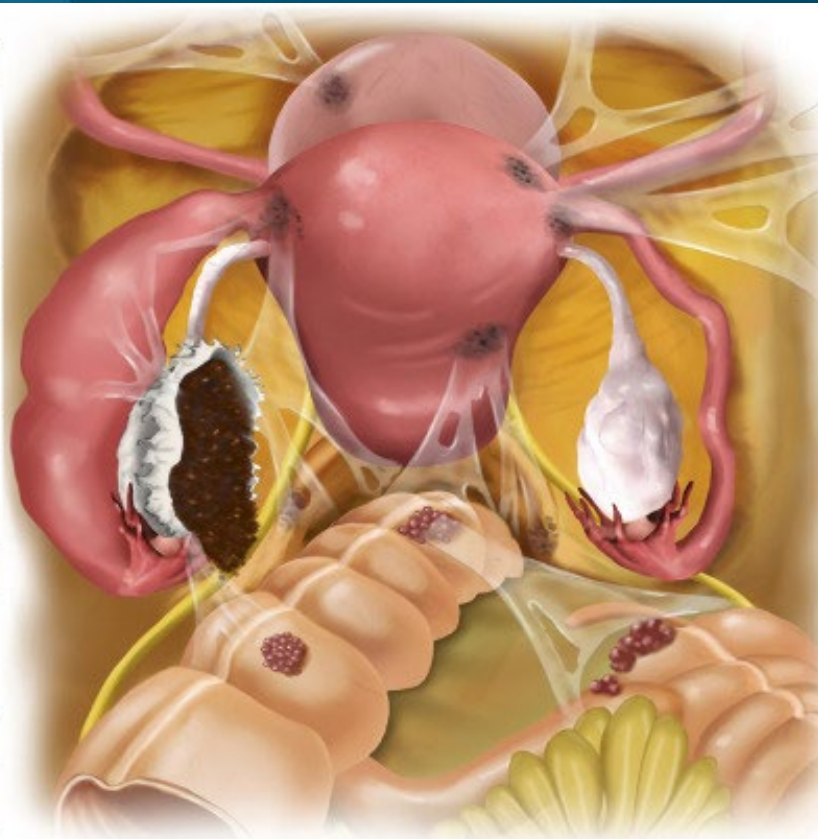
Lucarini E, et al. Visceral sensitivity modulation by faecal microbiota transplantation: the active role of gut bacteria in pain persistence. *Pain*. 2022 May 1;163(5):861-877. doi: 10.1097/j.pain.0000000000002438. PMID: 34393197; PMCID: PMC9009324.

# AAGL Staging System

|                                    |              |  |  |
|------------------------------------|--------------|--|--|
| <b>Superficial</b>                 | <b>Score</b> |  |  |
| < 3 cm                             | 2            |  |  |
| ≥ 3 cm                             | 4            |  |  |
| <b>Vagina (muscularis)</b>         | <b>Score</b> |  |  |
| < 3 cm                             | 5            |  |  |
| ≥ 3 cm                             | 8            |  |  |
| <b>Left Ovary</b>                  | <b>Score</b> |  |  |
| Superficial                        | 2            |  |  |
| < 3 cm                             | 5            |  |  |
| ≥ 3 cm                             | 7            |  |  |
| <b>Left Ureter</b>                 | <b>Score</b> |  |  |
| Extrinsic                          | 6            |  |  |
| Intrinsic                          | 8            |  |  |
| Hydroureter                        | 9            |  |  |
| <b>Left Fallopian Tube</b>         | <b>Score</b> |  |  |
| Slight serosal involvement /damage | 2            |  |  |
| Moderate immobility                | 4            |  |  |
| Severe immobility                  | 6            |  |  |
| Complete obstruction               | 7            |  |  |
| <b>Cul-de-sac obliteration</b>     | <b>Score</b> |  |  |
| Partial                            | 6            |  |  |
| Complete                           | 9            |  |  |
| <b>Rectum/ Sigmoid colon</b>       | <b>Score</b> |  |  |
| < 3 cm                             | 7            |  |  |
| ≥ 3 cm                             | 9            |  |  |
| <b>Rectovaginal septum</b>         | <b>Score</b> |  |  |
| Present                            | 8            |  |  |
| <b>Retrocervical</b>               | <b>Score</b> |  |  |
| < 3 cm                             | 5            |  |  |
| ≥ 3 cm                             | 8            |  |  |
| <b>Bladder/ detrusor</b>           | <b>Score</b> |  |  |
| < 3 cm                             | 5            |  |  |
| ≥ 3 cm                             | 7            |  |  |
| <b>Right Ovary</b>                 | <b>Score</b> |  |  |
| Superficial                        | 2            |  |  |
| < 3 cm                             | 5            |  |  |
| ≥ 3 cm                             | 7            |  |  |
| <b>Right Ureter</b>                | <b>Score</b> |  |  |
| Extrinsic                          | 6            |  |  |
| Intrinsic                          | 8            |  |  |
| Hydroureter                        | 9            |  |  |
| <b>Right Fallopian Tube</b>        | <b>Score</b> |  |  |
| Slight serosal involvement /damage | 2            |  |  |
| Moderate immobility                | 4            |  |  |
| Severe immobility                  | 6            |  |  |
| Complete obstruction               | 7            |  |  |
| <b>Small bowel/ Cecum</b>          | <b>Score</b> |  |  |
| < 3 cm                             | 6            |  |  |
| ≥ 3 cm                             | 8            |  |  |
| <b>Appendix</b>                    | <b>Score</b> |  |  |
| Present                            | 5            |  |  |

| AAGL Endometriosis Stage | Total Score |
|--------------------------|-------------|
| Stage 1                  | ≤8          |
| Stage 2                  | 9 to 15     |
| Stage 3                  | 16 to 21    |
| Stage 4                  | >21         |



Abrao MS, et al . AAGL 2021 Endometriosis Classification: An Anatomy-based Surgical Complexity Score. J Minim Invasive Gynecol. 2021 Nov;28(11):1941-1950.e1. doi: 10.1016/j.jmig.2021.09.709. Epub 2021 Sep 25. PMID: 34583009.

# New diagnostics

# New diagnostics

- A prescription-only test detects probable endometriosis based on signature of 109 microRNAs found in saliva. A multicenter validation study is still being finalized, with plans for clinical trial in the USA ahead of Food and Drug Administration (FDA) approval.
- Available several European countries
- Tested in two Ziwig-sponsored trials in France.
  - prospective study of 200 patients
  - interim analysis of another 200 women who had symptoms suggestive of endometriosis and underwent surgery
  - Ziwig claims the salivary test a sensitivity and specificity of over 95%.

# New diagnostics





# New diagnostics

- Next Gen Jane
- Developing a menstrual effluent collection tool, the Smart Tampon System (STS) collects RNA genomic signatures of endometrial tissue shed into a tampon during menstruation.



# New diagnostics

- Interleukin-6 as A Useful Predictor of Endometriosis-Associated Infertility: A Systematic Review
  - Been measured in EMBx specimens, serum follicular fluid and peritoneal fluid
  - Bias in current studies, needs for analysis



- Incognito, Giosuè & Guardo, et al. (2023). Interleukin-6 as A Useful Predictor of Endometriosis-Associated Infertility: A Systematic Review. International journal of fertility & sterility. 17. 226-230. 10.22074/ijfs.2023.557683.1329.

# Social media and endometriosis

The people are talking

# Perfect storm

- **Underfunded, understudied chronic disease**
- **High prevalence**
- **Young affected population**
- **Explosion of social media impact**
- **Erosion of trust in medical establishment**

# Social media and endometriosis

The Good

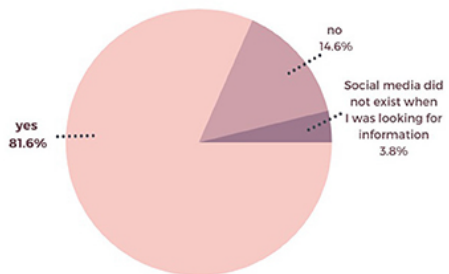
# What are patients reading?

## Social Media Information and Knowledge Practices of those with Endometriosis

Did your social media use teach you anything new about endometriosis that you did not hear about elsewhere?

Yes (92%)

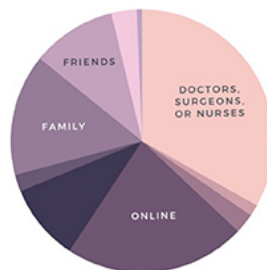
Did social media play any role in your process of seeking a diagnosis or learning about endometriosis?



results from 287 survey responses

Where did you first hear about endometriosis?

- 35% Doctors, surgeons, or nurses
- 1.5% Other practitioners (physiotherapists, accupuncturists, nutritionists)
- 2.6% Other health resources
- 23.6% Online
- 4.8% Other media (magazines, newspapers, TV)
- 2.2% Independent offline research
- 15.8% Family
- 11% Friends
- 3.3% School (grade school or nursing school)
- 0.7% Pharmaceutical commercials

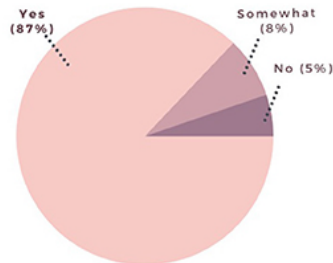


results from 271 survey responses

Did your social media use expose you to new or additional pain management treatments/tools?

Yes (66%)

Overall, have you found social media helpful in managing or living with your endometriosis?



results from 287 survey responses



< Endometriosis

Overview Symptoms Types and Stages Diagnosis Treatment

# The Top Endometriosis Instagrammers — and Why They're Important

These 14 women living with endometriosis are using social media to create a movement.

By Brianna MajsiaK  **Medically Reviewed** by Kacy Church, MD Updated on February 24, 2020



#endowarriors

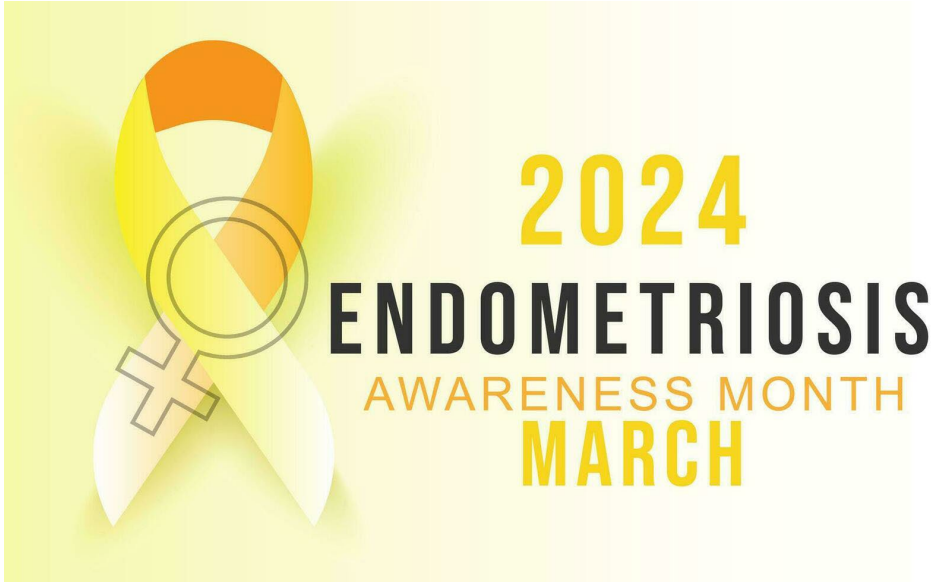
The Endometriosis Foundation

Nancy's Nook

EndoMetropolis

Heal.endo

endobelly





livingwithendometriosis\_\_

Follow Message ...

830 posts 44.8K followers 1,232 following

Emilia Victoria   
AKA @emiliovictoria   
 A Safe Space for People with Endometriosis   
 Endo Support Events   
 Sharing my Journey to help... more   
[linktr.ee/emiliovictoria](https://linktr.ee/emiliovictoria)



Discount Co...



Flare ups



TMixEndo E...



Surgery N.2



Fashion Tips

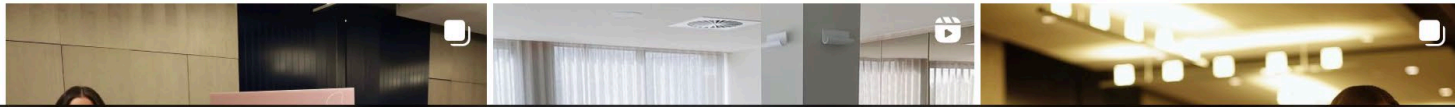


Podcast



Templates

POSTS REELS TAGGED







Dana Robinson:  
Organfuse (Copyright ©  
Dana Robinson, 2021)

- 76% respondents in a cross-sectional study used SM.
- 100% of users had positive feelings toward it
- “Positive impacts on ‘emotional stressors’ was the most commonly referenced health outcome. This included mitigating loneliness, building community, the emotionally therapeutic effect of sharing stories and experiences online and connecting to a shared narrative.”
- More symptomatic, more likely to use.
- “Use of SM did not always foster positive health outcomes. Consuming a large volume of negative narratives left some participants feeling over-whelmed, depressed and anxious regarding their own diagnosis and situation”

# Social media and endometriosis

The Bad

**Table 2.** Example of claims from Instagram posts about endometriosis.

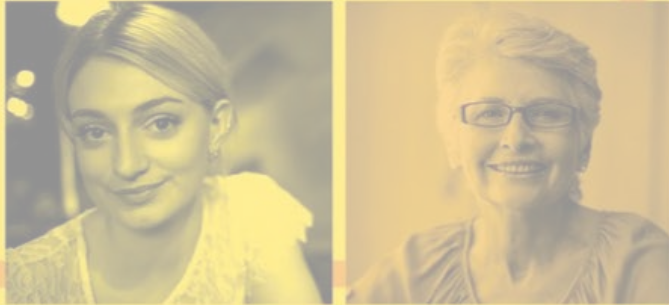
| Example Claim  |  |   |
|--|--|---|
| Evidence-Based   | Non-Evidence-Based   | Mixed   |
| <i>Endo[metriosis] can cause possible infertility (Fertility).</i>   | <i>Physiotherapy, psychology, analgesics and surgery do not relieve much pain (Orthodox Medicine).</i>                     | <i>If a patient has suspected endo[metriosis], they MUST be referred to an excision specialist (Surgery).</i>   |
| <i>For some, it [endometriosis] can prove to be excruciating, disrupting their normal routines and forcing them to plan their days around the pain (Symptoms).</i> | <i>The pill does not 'fix' anything and does not suppress bleeding for those with endo[metriosis] (Orthodox Medicine.)</i> | <i>It's [endometriosis] a chronic health issue that affects one in ten women and it's hardly ever talked about (Epidemiology).</i>  |
| <i>It takes on average eight years to get diagnosed (Diagnosis).</i>   | <i>20–25% of endo[metriosis] patients affected by infertility may be asymptomatic (Fertility).</i>                         | <i>Research has found that high levels of depression and anxiety can also exacerbate the symptoms of this condition. This is due to an increased pain perception which occurs with these psychological conditions (Scientific Article).</i> |
| <i>There is no cure for endometriosis (Cure).</i>  | <i>We do not need research into alternative therapies, MRI studies are useless (Alternative Medicine).</i>                 | <i>If a patient has endo[metriosis] so severe it can be seen on a DIE scan, it should be removed to prevent frozen pelvis and organ dysfunction and a range of other potential comorbidities (Pathophysiology).</i>                         |

Adler H, et al. Social Media, Endometriosis, and Evidence-Based Information: An Analysis of Instagram Content. *Healthcare*. 2024; 12(1):121.

<https://doi.org/10.3390/healthcare12010121>

# Social media and endometriosis

The Ugly



## CHARTING PATH TO BETTER ENDOMETRIOSIS

Supporting you to combat the disease, advocate for your health, and get the

“Here are some suggestions.

- Try to think long term. You may be irritated at your doctor right now, but you will need someone to follow you medically. If your current doctor is going to be that person, you need to navigate a way to keep the relationship cordial. Telling someone they're an idiot is not generally helpful, no matter how strong the urge is. Consider: you may have facts on your side from Nancy's Nook, but the patient your doctor saw before you was full of unscientific theories and nonsense. Your doctor may be suspicious when you come in with lots of details you learned from the Internet. That's not a bad position for them to take, because they're trying to protect you from incorrect information. You want to educate your physician, but not alienate them. So be open. Share what you've learned but remember that they went to medical school and may be wary.”

# Nancy's Nook Endometriosis Education

Private group · 203.3K members

## Find the Best Endometriosis Specialists and Experts

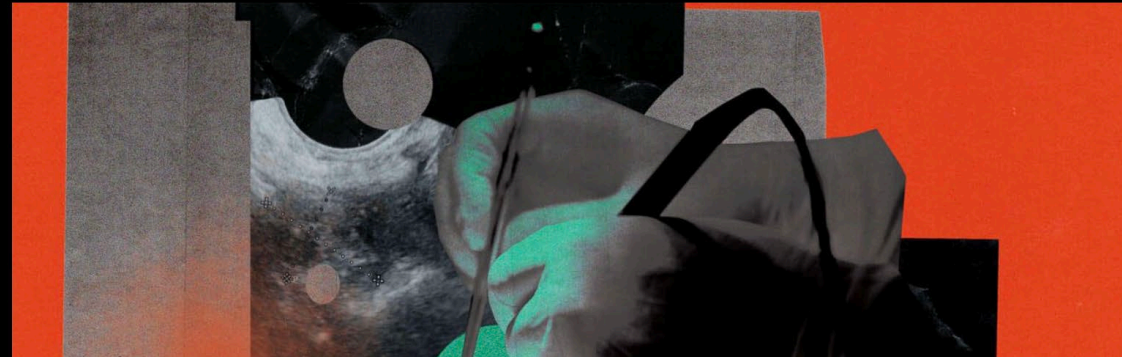
You need an endometriosis doctor near you who understands you and take your condition to heart.

Our endometriosis experts offer a full spectrum of care for endometriosis and pelvic pain, including diagnosis, surgery, and post surgical care.

### Find an Endometriosis Doctor Near You

# Endo Days

Are celebrity surgeons boosting awareness or their own brand?



# Treatment

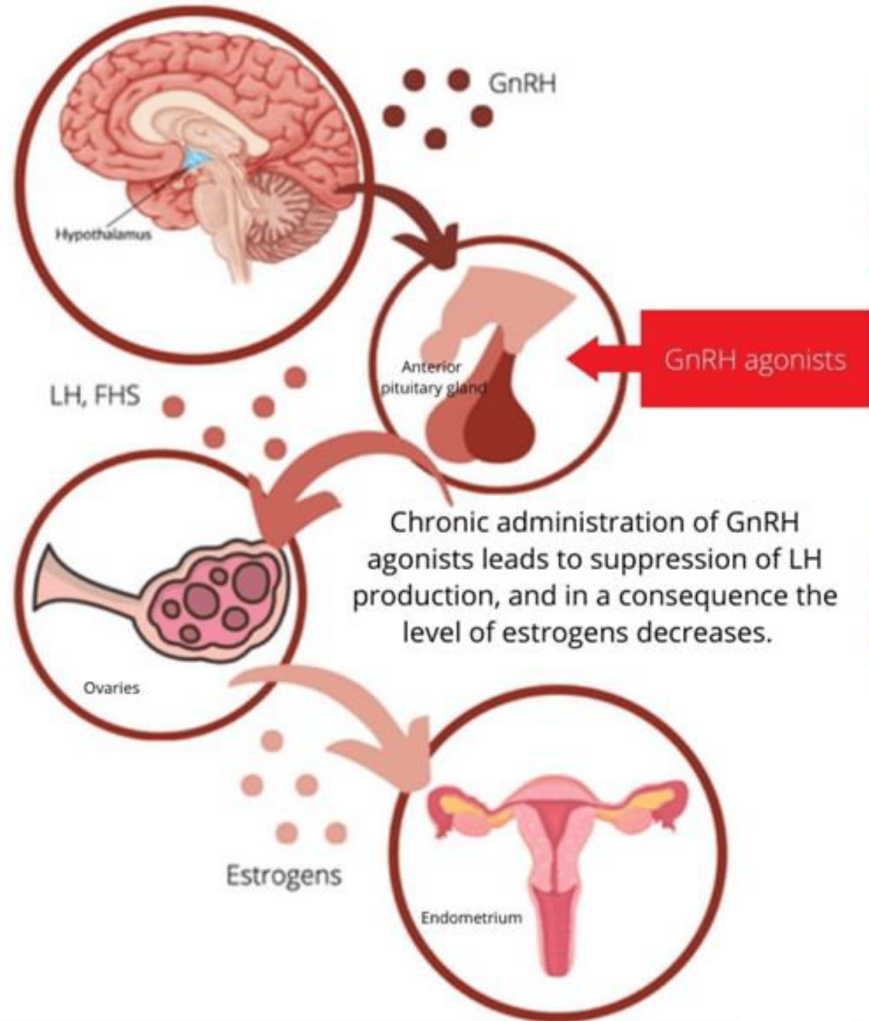
\*My favorites



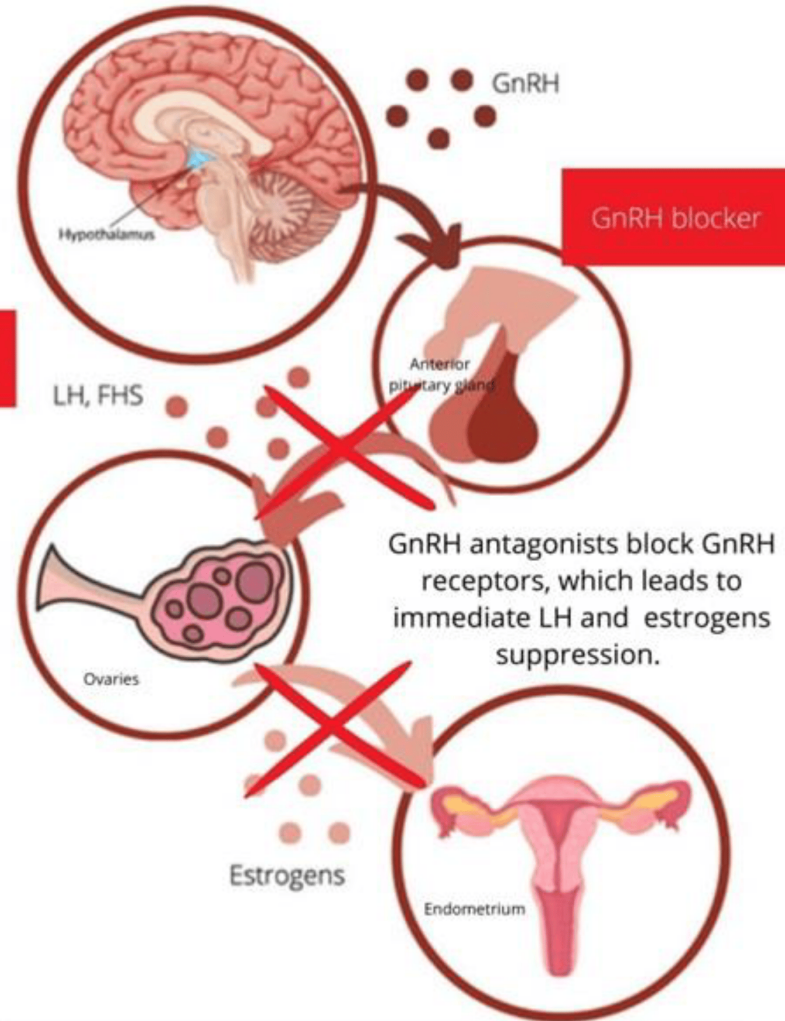
# Treatment

- Combined hormonal therapy + NSAID
- IUD
- Norethindrone 5mg
- Gabapentin

## GnRH agonists



## GnRH antagonists



# Elagolix

- One capsule (elagolix 150mg QD or 200mg BID for up to 24 months).
- FDA approved for treatment of mod to severe pain with endometriosis 2018



# Recommendations

- Intervene early. If first line therapies aren't helpful in an initial trial, consider dx LSC or referral.
- Recognize overlap between chronic pain and traumatic experiences
- Consider treatment with hormonal therapies, nerve modulators
- Consider non-gynecologic causes
- Encourage adjuncts, PFPT, social supports
- Affirm experiences. Remember the advice they are getting online.

**In 2018, "What is endometriosis?" was the third highest trending health-related question on Google. In the United States alone, there are more than 400,000 monthly Google searches of endometriosis.**

*Source: The Conversation*

VANDERBILT  UNIVERSITY  
MEDICAL CENTER