# MIGS 26

55TH GLOBAL CONGRESS ON MIGS

BOSTON, MASSACHUSETTS
NOVEMBER 13-16, 2026

# Syllabus

## General Session IV

Endometriosis Across the Lifespan:
Awareness, Access, Autonomy & Outcomes


HONORARY CHAIR
Charles H. Koh, MD

SCIENTIFIC PROGRAM CHAIR
Nash S. Moawad, MD

PRESIDENT
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**GSIV: General Session IV**
**Endometriosis Across the Lifespan: Awareness, Access, Autonomy & Outcomes**

**Chair:** Nash S. Moawad
**Faculty:** Philippa Bridge Cook, Jorge F. Carrillo, Shannon Cohn, Pauline de Corte, Lisa Eggebrecht, Jon I. Einarsson, Leigh A. Humphries, Ted T. Lee, Michelle Louie, Asha B. McClurg, Ricardo M.A. Pereira, Savannah Regensburger, Juan Diego Villegas-Echeverri, Lori B. Waxenberg
**Moderators:** Suzie As-Sanie, Megan Wasson

**Description:** For the first time in the history of the AAGL Global Congress, patients and surgeons will come together on the Main Stage to share experiences, challenges, innovations, and solutions in the care of endometriosis and complex pelvic pain disorders. This groundbreaking patient-centered session is designed to foster meaningful dialogue between patients, surgeons, multidisciplinary clinicians, and advocates while maintaining the scientific rigor and educational excellence that defines the AAGL. Through expert presentations, multidisciplinary discussion panels, live audience Q&A sessions, and powerful patient story videos, participants will explore barriers to diagnosis and treatment, advances in multidisciplinary care, and opportunities to improve awareness, access, outcomes, and autonomy for women worldwide. By bringing the patient voice directly into the Congress, this session aims to strengthen collaboration, empathy, and shared understanding between those delivering care and those living with these conditions.

**Learning Objectives**: *At the end of this course, the participant will be able to:* 1) Describe the lived experience of patients with endometriosis and chronic pelvic pain through direct dialogue with patients, surgeons, and multidisciplinary experts; 2) Examine emerging strategies to improve diagnosis, access to care, surgical outcomes, and long-term quality of life for women with pelvic pain disorders; and 3) Foster meaningful collaboration between patients, clinicians, advocates, and healthcare systems to shape the future of endometriosis care together.

**GS IV Course Outline**

| | | |
|---|---|---|
| **ACT I: UNDERSTANDING THE DISEASE** | | |
| 9:30 am | Patient Video: Why This Session Exists | |
| 9:32 am | Endometriosis Beyond Lesions: Caring for the Whole Patient | N. Moawad |
| 9:35 am | Seeing the Disease - A Patient-Oriented Anatomical Atlas: What's Really Happening Inside the Pelvis | R. Pereira |
| 9:45 am | What Patients Actually Experience - Real-World Data, Symptoms & Quality of Life – The LIDEA Registry | P. de Corte and L. Eggebrecht |
| 9:55 am | Patient Video: The Invisible Disease | |
| 9:57 am | Laparoscopic Excision of Endometriosis – Spectrum of Procedures, Options and Outcomes (Pain and Fertility Outcomes, Complications, Recurrence, Reoperation) | J. Einarsson |
| 10:12 am | Comfort Break | |
| **ACT II – DECISION MAKING ACROSS THE LIFESPAN** | | |
| 10:22 am | Introduction | N. Moawad |
| 10:23 am | Lifespan Based Care - From Adolescence to Menopause | M. Louie and A. McClurg |
| 10:35 am | Beyond Surgery: Lifestyle & Adjuncts: What the Evidence Actually Says - And What Doesn't Work | L. Humphries |

| | | |
|---|---|---|
| 10:45 am | Nutrition & Endometriosis - Eating for Endometriosis: Evidence-Based Dietary Modifications, Anti-Inflammatory Approaches & Fad Diets Debunked | S. Regensburger |
| 10:57 am | Shared Decision-Making Panel: Aligning Treatment with Patient Goals: Pain, Fertility, Function & Quality of Life<br>Moderator: M. Wasson | S. Cohn, P. Bridge-Cook, J. Einarsson, M. Louie, and S. Regensburger |
| 11:17 am | Comfort Break | |

**ACT III: LIVING WITH THE DISEASE**

| | | |
|---|---|---|
| 11:27 am | Introduction | N. Moawad |
| 11:28 am | Patient Video: When Treatment Isn't Enough | |
| 11:30 am | When the Calendar Predicts Pain: Breaking the Cycle of Anticipation, Anxiety, and Endometriosis | L. Waxenberg |
| 11:42 am | Why Surgery Isn't Enough? Persistent Pain After Treatment<br>Moderator: S. As-Sanie | J. Villegas-Echeverri and J. Carrillo |
| 11:57 am | Patient Video: What I Want You to Know | |
| 12:00 pm | Building Better Endometriosis Care: The Endometriosis Care Quality Collaborative | T. Lee |
| 12:10 pm | Questions and Answers<br>Moderator: M. Wasson | S. As-Sanie, J. Carillo, J. Villegas-Echeverri, T. Lee, L. Waxenberg |
| 12:30 pm | Closing: A Shared Beginning—Improving Endometriosis Care Together | N. Moawad |
| 12:35 pm | Adjourn | |

**ADA Statement:** In accordance with the Americans with Disabilities Act (ADA), please contact CMEsupport@aagl.org should you require any special assistance.

**Disclosure of Relevant Financial Relationships**
As an ACCME-accredited provider, AAGL is responsible for ensuring that accredited education is fair, balanced, free of commercial bias, and supports safe, effective patient care. AAGL maintains control over all aspects of educational planning, content, faculty selection, delivery, and evaluation.

All individuals in a position to control educational content are required to disclose financial relationships with ACCME-defined ineligible companies within the past 24 months. AAGL identifies and mitigates all relevant financial relationships before individuals assume their respective roles. Educational content is also subject to independent peer review by individuals without relevant financial relationships.

Disclosure information and acknowledgment of any commercial support are provided to learners before the activity to promote transparency and maintain the independence and integrity of the education.

Asterisk (*) denotes no financial relationships with ACCME-defined ineligible companies to disclose.

**PLANNER DISCLOSURES**
**The following members of AAGL have been involved in the educational planning and/or review of this course (listed in alphabetical order by last name).**

**PROFESSIONAL EDUCATION COMMITTEE**
Harold Wu, MD* - Chairman
Adrian Balica, MD*
Jamal Mourad, DO – Proctor: Intuitive Surgical
Jude Okohue, MD*
Steven Radtke, MD*
Anna Reinert, MD*
Jean Uy-Kroh, MD*
Linda Bradley, MD, AAGL Medical Director*
Linda Michels, AAGL Executive Director*
Linda Bell, AAGL Admin Support*
Nancy Williams, COO, CME Consultants*

**SCIENTIFIC PROGRAM COMMITTEE**
Nash Moawad, MD, MS, Chairman – Consultant (ended 12/2024): Medtronic, Womed, Integra Life Sciences
Amani Harris, MD*
Ted Lee, MD – Advisory/Consultant: Johnson & Johnson, Regeneron Pharmaceuticals
Nucelio Lemos, MD, PhD – Speakers Bureau: Pfizer, Inc., Medtronic; Advisory Board: Knight Therapeutics, Vecfer Pharma
Mario Malzoni, MD*
Emad Mikhail, MD – Consultant: Johnson & Johnson
Hannah Palin, MD*
Megan Wasson, DO*
Michael Hibner, MD, PhD*
Jose "Tony" Carugno, MD*
Angela Chaudhari, MD - Consultant: Tag/Dream Medical, Johnson & Johnson; Speakers Bureau: Johnson & Johnson
Linda D. Bradley, MD, Medical Director*
Linda Michels, Executive Director, AAGL*

**COURSE CHAIR DISCLOSURE**
Nash S. Moawad, MD, MS, FACOG, FACS – Consultant: Integra LifeSciences, Medtronic, Womed

**COURSE MODERATORS' DISCLOSURES**
Megan Wasson, DO*
Sawsan As-Sanie, MD, MPH – Consultant: Gesynta, Lilly, UCB Biopharma

**FACULTY DISCLOSURES**
**The following faculty have agreed to support their presentations and clinical recommendations with the best available evidence from the medical literature (in alphabetical order by last name).**
Philippa Bridge Cook*
Jorge F. Carrillo, MD, FACOG, MHPE – Speakers Bureau: Vertex
Shannon Cohn*
Pauline de Corte, MD*
Juan Diego Villegas-Echeverri, MD, FRCPI, PPSD*
Lisa Eggebrecht, PhD*
Jon Ivar Einarsson, MD, PhD, MPH – Employed Relationship: Freyja Healthcare
Leigh A Humphries, MD MSCE*
Ted TM Lee, MD – Consultant: Anuat, Jmees, Johnson & Johnson, Regeneron
Michelle Louie, MD, MSCR, FACOG – Consultant: Hologic
Asha B. McClurg, MD*
Nash S. Moawad, MD, MS, FACOG, FACS – Consultant: Integra LifeSciences, Medtronic, Womed
Ricardo M A Pereira, MD*
Savannah Regensburger, MS, MBA, CNS*
Megan Wasson, DO*
Lori B. Waxenberg, PhD, ABPP*

**MITIGATION OF RELEVANT FINANCIAL RELATIONSHIPS**
**All relevant financial relationships have been mitigated.**
Drs. Lee, Lemos, Mikhail, and Chaudhari's planning decisions, as part of the Scientific Program Committee (SPC), were peer reviewed by other planners on the SPC who had disclosed no financial relationships with ineligible companies, and found to be fair, balanced, and free of commercial bias. Dr. Moawad's financial relationships ended 12/2024, thus mitigating them. For most of his AAGL Professional Education Committee service, Dr. Mourad had no financial relationships to disclose. He recently disclosed a new relationship as a Proctor for Intuitive Surgical. Since then, he has not participated in activities involving control or influence over accredited educational content; therefore, no additional mitigation was necessary.

Relevant financial relationships were mitigated through independent peer review of educational content and planning decisions by individuals without relevant financial relationships. Dr. Moawad, in his role as Course Chair, had all planning and oversight responsibilities subject to independent review. Dr. As-Sanie, in her role as moderator, and all faculty serving as panelists without formal presentation content attested to maintaining balance, independence, objectivity, and scientific rigor and ensuring discussions remain free of commercial bias. Faculty presentations for Drs. Carillo, Einarsson, and Louie, underwent independent peer review and were confirmed to be fair, balanced, and free of commercial bias.

## *Seeing the Disease – A Patient-Oriented Anatomical Atlas*





*Ricardo M A Pereira*

*Center for Endometriosis, Neuropelveology and MIGS*
*Santa Joana Hospital and Maternity - Sao Paulo - Brazil*
*Associate Professor, Faculty of Medical Science - Belo Horizonte - Brazil*

1

**FINANCIAL DISCLOSURE**

**Ricardo M. A. Pereira, MD**

Inventor and patent holder of the **Life Surgery Box**,
a system for synchronized capture and storage of clinical-surgical data.

**U.S. Patent No. 12,211,605 B2**

The technology is currently being developed for potential commercial use.

2

Título

## Endometriosis: Inflammation





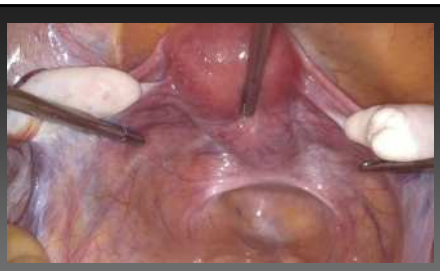


*Rheumatoid arthritis* *Endometriosis* *Irritable bowel syndrome*

*Wei et al. Journal of Neuroinflammation - 2020*

3

3



## Normal Pelvic Anatomy

4



## Normal Upper Abdominal Anatomy

**Subphrenic and Subhepatic Recesses**

5

## Pelvic Neuroanatomy

**Visceral Nervous System**

**Efferent (Motor)**

- Motor innervation of visceral smooth muscle and glands
- Visceral Motor System (Autonomic Nervous System)

**Afferent (Sensory)**

- Transmits noxious stimuli and other interoceptive sensations from the abdominal and pelvic viscera, including their covering visceral peritoneum.

**Somatic Nervous System**

**Efferent (Motor)**

**Afferent (Sensory)**

Rogers RM Jr. In: Steege JF, et al., eds. Chronic Pelvic Pain: An Integrated Approach. WB Saunders; 1998:31–58.

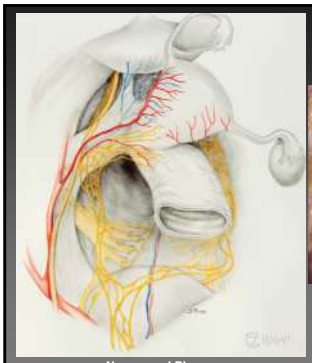
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## Pelvic Neuroanatomy

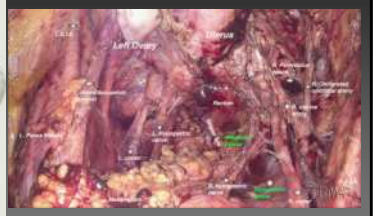


1. Superior Hypogastric Plexus
2. Hypogastric Nerves
3. Sacral Roots
4. Pelvic Splanchnic Nerves
5. Sciatic Nerve
6. Inferior Hypogastric Plexus
7. Uterine Nerve
8. Intestinal Nerve
9. Vesical Nerve

7



Nerves and Plexus



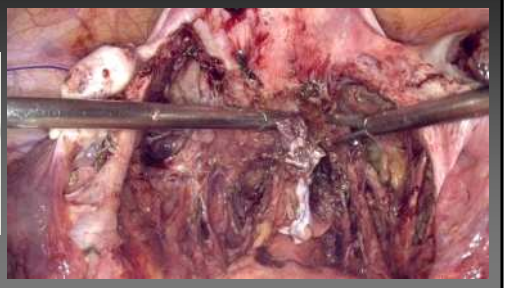

Subperitoneal Pelvic Connective Tissue

8

## Pelvic Neuroanatomy



Nerves and Plexus



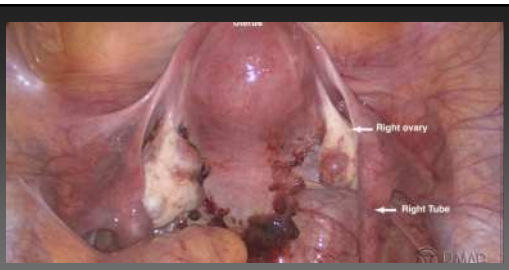
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## Appearances of Peritoneal Endometriosis

Black: Typical puckered black lesions

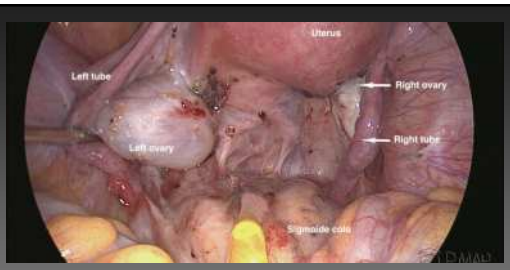
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## Appearances of Peritoneal Endometriosis

Black: Typical puckered black lesions

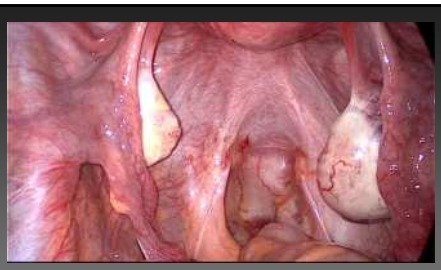
11




## Appearances of Peritoneal Endometriosis

Black: Typical puckered black lesions

12



## Appearances of Peritoneal Endometriosis

Red: Atypical Lesions

13



## Appearances of Peritoneal Endometriosis

White: Atypical Lesions

14

## Types of Endometriotic Lesions

***Superficial Endometriosis***



***Deep Endometriosis***



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## Symptoms of Endometriosis: Pelvic Pain



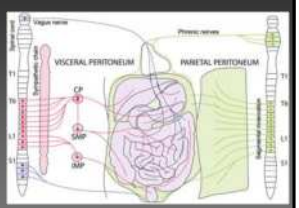


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## Symptoms of Endometriosis: Pelvic Pain





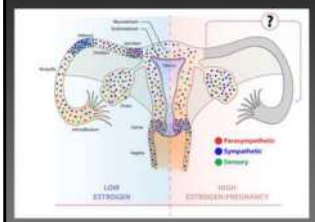



Struller F. *Peritoneal innervation: embryology and functional anatomy*

**Abdominal bloating**

17

## Symptoms of Endometriosis: Dysmenorrhea

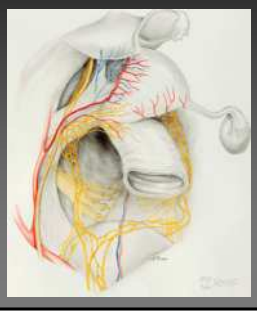




*Brauer and Smith, Auton Neurosci. 2016*

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## Symptoms of Endometriosis: Cyclic Low Back Pain



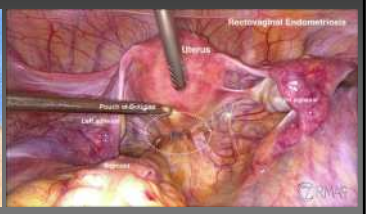


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## Symptoms of Endometriosis: Deep Dyspareunia



Vaginal view




Laparoscopic view

20

## Symptoms of Endometriosis: Premenstrual and Postmenstrual Spotting






Premenstrual and Postmenstrual Spotting

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## Symptoms of Endometriosis: Urinary Urgency and Frequency




22

## Bladder Endometriosis



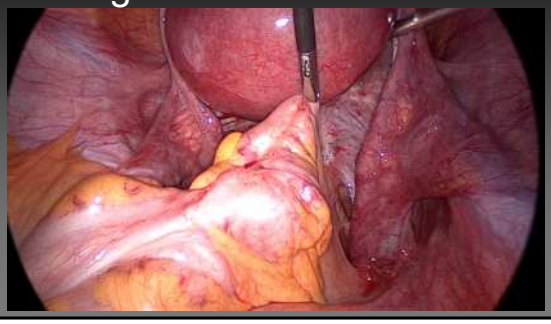

23

## Symptoms of Endometriosis: Dyschezia



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## Sigmoid Endometriosis



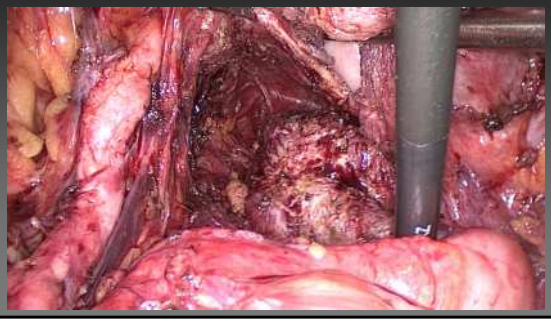
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## Rectovaginal Endometriosis



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## Rectal Endometriosis



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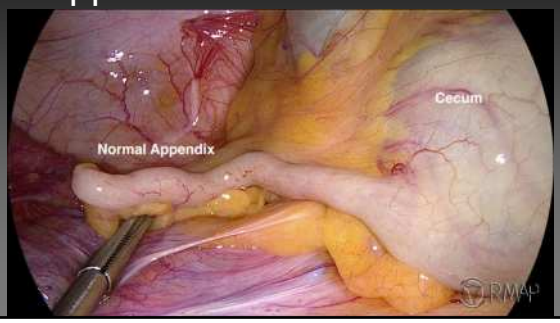


## Sciatic Nerve Endometriosis

**Cyclic Sciatica**

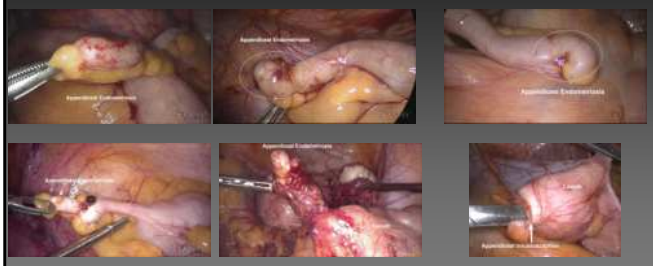
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## Appendiceal Endometriosis



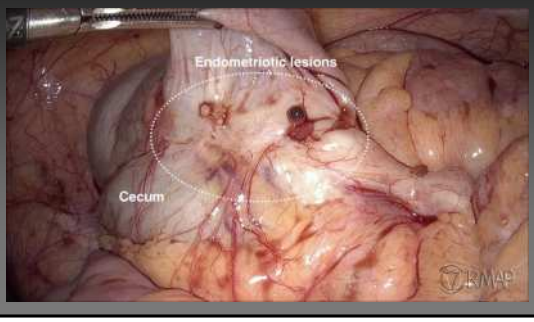

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## Appendiceal Endometriosis



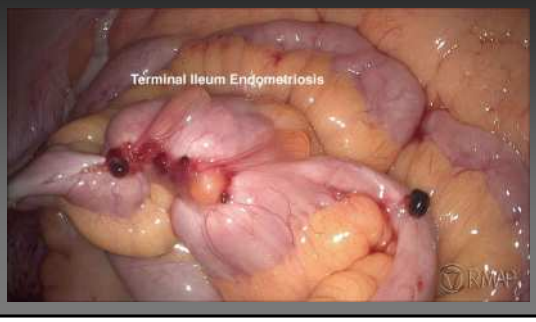
30

## Cecal Endometriosis




31

## Terminal Ileal Endometriosis




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DIAPHRAGMATIC ENDOMETRIOSIS

## Thoracic Extension



Diaphragmatic Endometriosis



Visceral Pleural Endometriosis

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## Right Diaphragmatic Endometriosis: Symptoms

- Pain associated with breathing
- Chest pain
- Pain when lying supine
- Epigastric pain
- Right upper quadrant pain

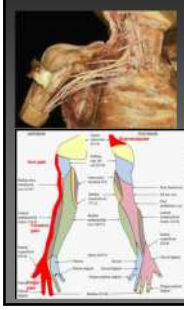
Pain relief: heating pads, ice packs, massage, analgesics, and sleeping in a sitting or antalgic position

***Redwine DB. Surgical Management of Endometriosis. Tottenham Court, London, 2004.***

***Redwine DB***. Diaphragmatic endometriosis: diagnosis, surgical management, and long-term results of treatment. Fertil Steril. 2002.

34

## Referred Pain



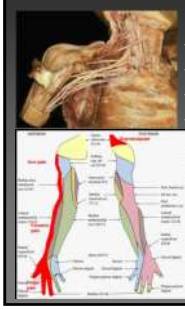
- Neck *****
- Suprascapular region ******
- Arm **
- Forearm *
- Fingers *



Cyclic neuropathic pain during menstruation and ovulation

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## Right Diaphragmatic Endometriosis



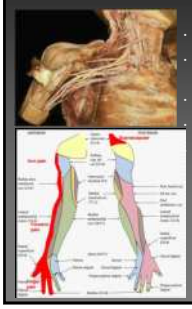
- Neck *****
- Suprascapular region ******
- Arm **
- Forearm *
- Fingers *




Neuropathic pain during menstruation and ovulation

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## Right Diaphragmatic Endometriosis



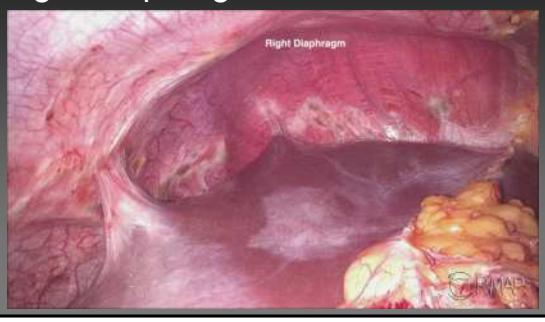
- Neck *****
- Suprascapular region ******
- Arm **
- Forearm *
- Fingers *



Neuropathic pain during menstruation and ovulation

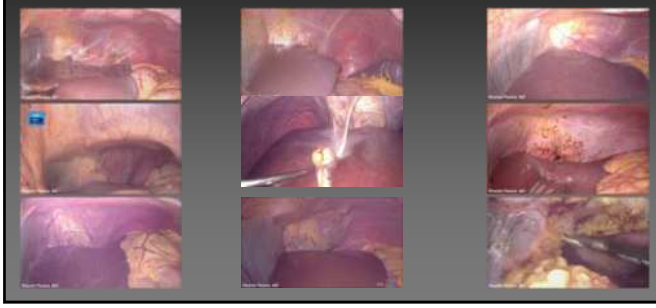
37

## Right Diaphragmatic Endometriosis



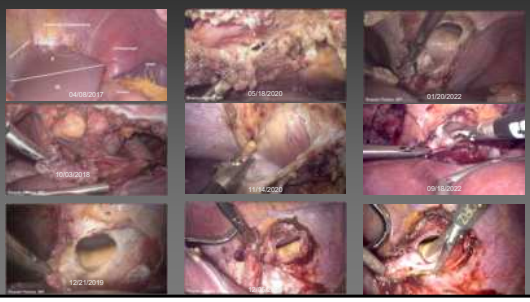

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## Pericardial Endometriosis

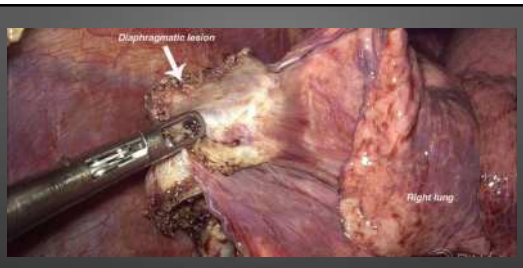


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## Pericardial Endometriosis



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Endometriosis Involving the Right Thoracic Cavity

Diaphragmatic Endometriosis Infiltrating the Lung

41

THANK YOU

*For seeing the disease through the patient's perspective.*

**Ricardo M. A. Pereira, MD**
São Paulo, Brazil

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# What Patients Actually Experience: Real-World Data, Symptoms & Quality of Life – The LIDEA Registry

Pauline De Corte, PhD · ZEG Berlin

Lisa Eggebrecht, PhD · ZEG Berlin

NOVEMBER 13-16, 2026 · BOSTON · #AAGL26

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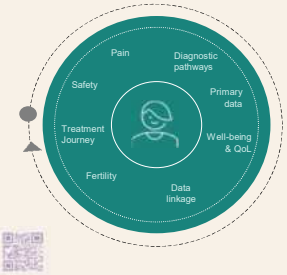
## Disclosure

- *We have no financial relationships to disclose.*
- *ZEG Berlin has received funding from Organon to support the initiation of the study in Germany.*
- *The research team has no financial conflicts of interest to disclose, and the registry is overseen by an independent Key Opinion Leader Board.*

2

## LIDEA REGISTRY

*Long-term International Dual-Source Endometriosis and Adenomyosis Registry*




**KEY FEATURES**

- Longitudinal registry
- Patient-centric
- Endometriosis, Adenomyosis
- Pain & Bleeding
- Treatment pathways
- Under-researched & diverse populations

3

## LIDEA REGISTRY

*Long-term International Dual-Source Endometriosis and Adenomyosis Registry*

**BENEFITS**

- Patient data is important in understanding the full disease journey.
- Some outcomes reported by patients cannot be easily identified from other data sources (e.g. clinical data, claims data) but are important to improve diagnostic and treatment options.



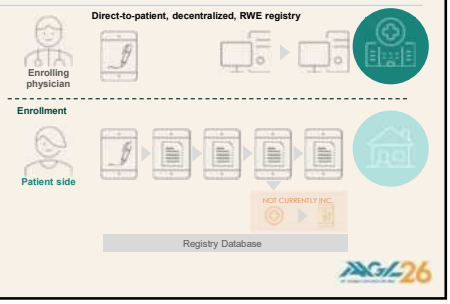

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## METHODOLOGY

**"Patient-centered" methodology**
**"Dual Source"**

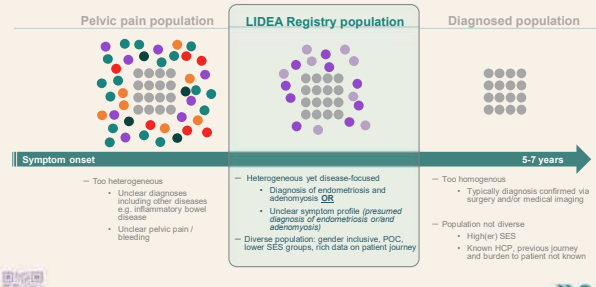
**KEY FEATURES**

- Study participant is recruited by "enrolling physician" who provides access to a study portal for eConsent & baseline survey.
- Broad physician base for recruitment - Family Phys, ObGyn, Pelvic Pain groups
- Follow-up directly with study participant via study portal.
- Key medical outcomes obtained from the enrolling physician during 2 touchpoints (12 and 36 months)




5

## REGISTRY POPULATION




6

## DATA COLLECTION

LIDEA

SCHEDULE

| | Baseline | 6 months | 12 months | 24 months | 36 months |
|---|---|---|---|---|---|
| Study participant | | | | | |
| Study-specific questionnaire | x | x | x | x | x |
| EPDD *(30 days pain diary)* | x | x | x | | |
| EHP30 | x | x | x | x | x |
| COPC Screener | x | | x | x | x |
| Physician | | | | | |
| Study-specific questionnaire | x | | x | | x |

7




8

## CURRENT STATUS

LIDEA



GERMANY

- Pilot study activated in Germany in December 2025
- Aim to recruit 2,000 German participants and expand to other countries

9

## ABOUT THE PATIENT

LIDEA



1. Mean age: 36,5 yrs (youngest: 24, oldest: 49)
2. Physician Confirmed Diagnosis: 96%
   - I. Symptoms: 17%
   - II. Surgical procedure: 67%
   - III. Imaging test: 16%

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## THE SYMPTOMS

LIDEA

1. Had symptoms in the past 3 months 56%
2. Of which, reported 3 or more symptoms simultaneously: 93%
   - I. Painful periods: 57%
   - II. Pelvic pain unrelated to period pain 57%
   - III. Pain when passing urine 29%
   - IV. Pain during or after sexual intercourse **71.5%**
   - V. Pain during bowel movement 50%
   - VI. Constipation or diarrhea **71.5%**
   - VII. Tiredness/Weakness **78.5%**
   - VIII. Heavy Bleeding 43%
   - IX. Irregular Bleeding 7%
   - X. Infertility 14%

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## THE SYMPTOMS (II)

LIDEA

1. Had symptoms in the past 3 months 56%
2. Of which, reported 3 or more symptoms simultaneously: 93%
   - I. Painful periods: 57%
   - II. Pelvic pain unrelated to period pain 57%
   - III. Pain when passing urine 29%
   - IV. Pain during or after sexual intercourse **71.5%**
   - V. Pain during bowel movement 50%
   - VI. Constipation or diarrhea **71.5%**
   - VII. Tiredness/Weakness **78.5%**
   - VIII. Heavy Bleeding 43%
   - IX. Irregular Bleeding 7%
   - X. Infertility 14%

43% of patients reported that symptoms are **cyclical**

57% of patient reported **constant** symptomatic

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## THE SYMPTOMS (III)

3. Pain
   - No pain 7.1%
   - Mild 42.9%
   - Moderate 35.7%
   - Severe 14.3%

4. Triggers that worsen symptoms 64%
   - I. Stress (35%)
   - II. Food (21%)
   - III. Other (8%)

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## DIAGNOSTIC DELAY

| Time between symptoms and diagnosis | |
|---|---|
| I had no symptoms leading to a diagnosis | 8.0% |
| Less than 6 months | 8.0% |
| 6 months to 1 year | 12.0% |
| More than 1 year up to 2 years | 4.0% |
| More than 2 years up to 3 years | 4.0% |
| **More than 3 years up to 4 years** | **20.0%** |
| More than 4 years up to 5 years | 4.0% |
| More than 5 years up to 6 years | 4.0% |
| More than 6 years up to 7 years | 4.0% |
| More than 8 years up to 9 years | 4.0% |
| More than 9 years up to 10 years | 4.0% |
| More than 10 years up to 11 years | 8.0% |
| More than 11 years up to 12 years | 8.0% |
| More than 15 years | 8.0% |

40% of patients still have a diagnostic delay of +5 years

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## TREATMENT

1. Surgical treatment 68%
2. Hormonal treatment 68%
   - I. Take hormones continuously: 59%
3. Pain-killers (prescribed and OTC) 57%
4. Alternative therapies 44%
5. Overall treatment satisfaction:
   - *Very dissatisfied* 7%
   - *Dissatisfied* 7%
   - *Neither dissatisfied/satisfied* 40%
   - *Satisfied* 20%
   - *Very satisfied* 27%



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## THE IMPACT

No effect on my **work/school/daily activities**

| | |
|---|---|
| 0 | 26% |
| 1 | 11% |
| 2 | 11% |
| 3 | 16% |
| 4 | 11% |
| 5 | 0% |
| 6 | 16% |
| 7 | 11% |
| 8 | 0% |
| 9 | 0% |
| 10 | 5% |

Completely prevents me from working/school/daily activities

No effect on my **social activities**

| | |
|---|---|
| 0 | 39% |
| 1 | 0% |
| 2 | 22% |
| 3 | 4% |
| 4 | 4% |
| 5 | 4% |
| 6 | 13% |
| 7 | 9% |
| 8 | 0% |
| 9 | 4% |
| 10 | 0% |

Completely prevents me from social activities

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## EHP30

During The Last 4 Weeks, Because Of Your Endometriosis, How Often Have You...

| | Never | Rarely | Sometimes | Often | Always |
|---|---|---|---|---|---|
| PHYSICAL ACTIVITY | | | | | |
| 1. Been **unable** to go to **social** events because of the pain? | | | | | |
| 2. Been **unable** to do **jobs around the house** because of the pain? | | | | | |
| 3. Found it **difficult to stand** because of the pain? | | | | | |
| 4. Found it **difficult to sit** because of the pain? | | | | | |
| 5. Found it **difficult to walk** because of the pain? | | | | | |
| 6. Found it **difficult to exercise** or do the leisure activities you would like to do because of the pain? | | | | | |
| 7. Lost your **appetite** and/or been unable to eat because of the pain? | | | | | |
| 8. Been unable to **sleep** properly because of the pain? | | | | | |
| 9. Had to **go to bed/lie down** because of the pain? | | | | | |
| 10. Been unable to do the **things you want** because of the pain? | | | | | |
| 11. Felt unable to **cope** with the pain? | | | | | |
| 12. Generally **felt unwell**? | | | | | |
| 13. Felt **frustrated** because your symptoms are not getting better? | | | | | |
| 14. Felt **frustrated** because you are not able to control your symptoms? | | | | | |
| 15. Felt unable to **forget** your symptoms? | | | | | |

60-70% 10-20% 60-70% 10-20%

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## EHP30

During The Last 4 Weeks, Because Of Your Endometriosis, How Often Have You...

| | Never | Rarely | Sometimes | Often | Always |
|---|---|---|---|---|---|
| EMOTIONAL IMPACT | | | | | |
| 16. Felt as though your **symptoms are ruling your life**? | | | | | |
| 17. Felt your **symptoms are taking away your life**? | | | | | |
| 18. Felt **depressed**? | | | | | |
| 19. Felt **weepy/tearful**? | | | | | |
| 20. Felt **miserable**? | | | | | |
| 21. Had **mood swings**? | | | | | |
| 22. Felt **bad-tempered** or **short-tempered**? | | | | | |
| 23. Felt **violent or aggressive**? | | | | | |
| 24. Felt **unable to tell others how you feel**? | | | | | |
| 25. Felt **others do not understand** what you are going through? | | | | | |
| 26. Felt as though others think you are **whining**? | | | | | |
| 27. Felt **alone**? | | | | | |
| 28. Felt **frustrated** that you cannot always wear the clothes you would choose? | | | | | |
| 29. Felt your **appearance** has been affected? | | | | | |
| 30. Lacked **confidence**? | | | | | |

60-70% 20-25%

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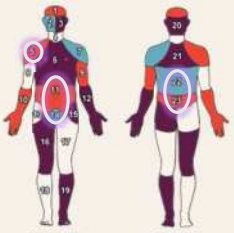
## COPCS




1. Fibromyalgia
2. Temporomandibular disorder
3. Chronic low back pain
4. Migraine / Chronic tension-type headache
5. Irritable bowel syndrome
6. Myalgic Encephalmyelitis / CFS
7. Vulvodynia
8. Endometriosis

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## OVERLAPPING PAIN

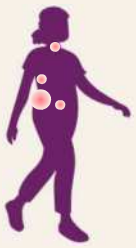



| Body Area | Percentage |
|---|---|
| Area 1 (top of head) | 25% |
| Area 2 (right jaw) | 4% |
| Area 3 (left jaw) | 12.5% |
| Area 4 (neck) | 12.5% |
| Area 5 (right shoulder) | **20.8%** |
| Area 6 (chest) | 16.7% |
| Area 7 (left shoulder) | 8.3% |
| Area 8 (right upper arm) | 4% |
| Area 9 (left upper arm) | 4% |
| Area 10 (right lower arm) | 8.3% |
| Area 11 (abdomen) | **33.3%** |
| Area 12 (left lower arm) | 12.5% |
| Area 13 (right hip/buttock) | 16.7% |
| Area 14 (pelvis/genitals) | **33.3%** |
| Area 15 (left hip/buttock) | 12.5% |
| Area 16 (right upper leg) | 8.3% |
| Area 17 (left upper leg) | 8.3% |
| Area 18 (right lower leg) | 12.5% |
| Area 19 (left lower leg) | 12.5% |
| Area 20 (back of head) | 8.3% |
| Area 21 (upper back) | 8.3% |
| Area 22 (lower back) | **8.3%** |
| Area 23 (lower back) | **29.2%** |

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## CONCOMITTANT DISEASES

1. Reported physician-diagnosed concomitant disease: 50%



| | |
|---|---|
| Scoliosis (curvature of the spine) | **41.6%** |
| Hashimoto's disease | **41.6%** |
| Spine problems (excluding scoliosis) | **25.0%** |
| Asthma | 16.7% |
| Chronic Fatigue Syndrome | 8.3% |
| Depression requiring treatment | 8.3% |
| Diabetes requiring insulin or tablets | 8.3% |
| Fibromyalgia | 8.3% |
| High Blood Pressure requiring treatment | 8.3% |
| Multiple Sclerosis | 8.3% |
| Pelvic Inflammatory Disease | 8.3% |
| Polycystic Ovary Syndrome | 8.3% |
| Thyroid disease requiring treatment | 8.3% |
| Ulcerative colitis | 8.3% |
| Cancer | 8.3% |
| Irritable Bowel Syndrome | 8.3% |
| Rheumatoid Arthritis | 8.3% |
| Spine problems (excluding scoliosis) | 8.3% |

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## EPDD



22

## PRELIMINARY CONCLUSION

- Patients with endometriosis are very motivated to provide data
- LIDEA Registry collects data that could help answer many unresearched areas
- Data currently is limited but already extremely valuable showing:
  - *Disease heterogeneity*
  - *Treatment heterogeneity*
  - *Impact on patient's life*
  - *Impact on the health care system*
  - *Small but consistent subgroup that is highly affected (emotional & physical)*
- Future follow-up & physician data will complete the patient journey more accurately

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## OUR GOAL




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## OUR GOAL

**Connecting single research projects into a global data source**

Aiming to improve:

1. **The global understanding** of the heterogeneity of endometriosis and adenomyosis
2. **Standardized data availability** to conduct qualitative research in the field
3. **Patients' disease trajectories** and individualized treatment options
4. **Diagnostic and treatment options** for caregivers
5. **A registry that can be amended** according to the timely needs of these conditions in light of new research advancements

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## VISIT OUR WEBSITE




**We are open for any collaboration!**

**Do not hesitate to contact us**

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## Acknowledgments

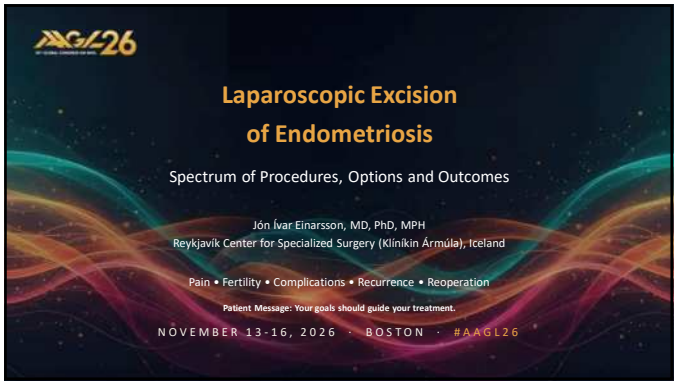

- Pauline De Corte, PhD, Berlin Center for Epidemiology and Health Research GmbH (ZEG Berlin).
- Lisa Eggebrecht, PhD, Berlin Center for Epidemiology and Health Research GmbH (ZEG Berlin).
- Klaas Heinemann, Dr., Berlin Center for Epidemiology and Health Research GmbH (ZEG Berlin).


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## References


- All data, analyses, figures, and graphical representations presented herein are based on proprietary study data and internal analyses of ZEG Berlin.
  No external sources were used unless explicitly stated.


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## Disclosure

**Founder and equity owner: Freyja Healthcare**

02

2

## Objectives

By the end of this talk, you will be able to:

- Describe the main operations used to treat endometriosis.
- Compare potential benefits and risks for pain and fertility.
- Identify questions that support a personal treatment and follow-up plan.

PATIENT MESSAGE **You have options—and a voice in the plan.**

03

3

## Different disease, different operation

These forms can occur together.

| Surface lesions | Ovarian cysts | Deep disease |
|---|---|---|
| On the peritoneum (lining of the pelvis). | Endometriomas within an ovary. | In or near bowel, bladder, ureters or supporting tissues. |

PATIENT MESSAGE **Your operation should fit your disease.**

04

4

## Why early identification matters

Early intervention may reduce disease progression, preserve fertility and reduce central sensitization

| Recognize & treat | Follow up & plan | Escalate when needed |
|---|---|---|
| Pain that disrupts school, work or daily life deserves assessment and care. | Check treatment response and discuss future pregnancy goals early. | Persistent or worsening symptoms call for reassessment and specialist care. |

PATIENT MESSAGE **You should not have to wait years to be heard and helped.**

Stuart et al. • Submitted ACTA review

05

5

## What can the surgeon do?

Laparoscopic surgery uses small incisions; the work inside can vary greatly. Surgeon experience matters.

| Excision / ablation | Ovarian surgery | Deep disease surgery |
|---|---|---|
| Remove lesions / destroy selected lesions. | Remove the cyst wall or use selected tissue-sparing techniques. | Bowel shaving, disc removal or segment removal; bladder or ureter surgery. |

PATIENT MESSAGE **Small incisions do not always mean a small operation.**

ESHRE 2022

06

6

## Excision or ablation?

The answer depends on the type of disease.

**Surface disease**

Excision is probably better, although the evidence is not conclusive

**Ovarian cysts**

Cystectomy reduces cyst recurrence versus drainage and ablation. Endometriosis and removal damage the ovary

**Deep disease**

Removal can help symptoms; the extent of surgery must balance benefit and risk.

PATIENT MESSAGE **Ask why a particular technique is right for you.**

ESHRE 2022 • Burks 2021 • Cochrane 2024 07

7

## Can surgery improve pain?

Many patients report meaningful improvement—but there is no guarantee.

**Median quality-of-life rating / 100**




**4,721 patients**
**Specialist-centre deep disease**
Observational study; not a promise of individual benefit.

PATIENT MESSAGE **Relief is possible; your likely benefit deserves an honest discussion.**

Byrne 2018 • Cochrane 2020 08

8

## If pain remains, it is still real

Lesions are one possible contributor to pelvic pain.

**Endometriosis / adenomyosis**

Disease can remain or coexist in the uterus.

**Muscles & nearby organs**

Pelvic-floor, bladder or bowel problems may contribute.

**Sensitive nerves**

Nerves can remain more sensitive after lesions are treated.

PATIENT MESSAGE **Persistent pain needs care—not blame.**

Orr 2023 09

9

## Can surgery help natural pregnancy?

Modest benefit in patients with mild disease in randomized trials. No randomized trials for deep disease.

**What trials show**

Treating lesions significantly increased chance of pregnancy beyond 20 weeks (NNT=8).

**Limitations**

Relatively old data from 1990's. Both ablation and excision used.

**What guides your choice**

Age, other fertility factors, ovarian function and your preferences.

PATIENT MESSAGE **Discuss the chance of pregnancy—and the time you can afford to wait.**

Cochrane 2020 • ESHRE 2022 10

10

## Protecting the ovaries matters

Surgery and IVF can be complementary—but the sequence matters.

**Ovarian reserve**

Endometrioma surgery can reduce the remaining egg supply. Ideally do egg retrieval before surgery.

**Before IVF**

Routine endometrioma removal solely to improve live birth is not recommended.

**Deep disease**

A fertility benefit from surgery is uncertain (some studies show benefit); pain and organ needs also matter.

PATIENT MESSAGE **A cyst does not automatically need surgery before IVF.**

ESHRE 2022 • Cochrane 2024 11

11

## Complications: ask about your operation

Risk rises with complexity and the organs involved.

**6.8%**
Overall complications

**1.1%**
Bowel injury, leak or fistula

**1.0%**
Urinary-tract injury or leak

Deep rectovaginal surgery at specialist centres; categories overlap.

PATIENT MESSAGE **Ask for risks specific to the procedure and the team.**

Byrne 2018 12

12

## “Coming back” can mean three things

These outcomes should not be mixed into one percentage.

**Persistent / returning pain**

Symptoms never fully resolve or return later.

**Lesion recurrence**

Disease is detected again on imaging or at surgery.

**Reoperation**

Another operation is performed—for several possible reasons.

PATIENT MESSAGE **Returning pain does not automatically mean you need surgery.**

Zakhari 2021 • Roman 2023 13

13

## How often is another operation needed?

The answer changes with follow-up and the patients studied.

**~11%**

Pooled across 57 studies
Different follow-up periods

**One separate long-term series**

**18%** at 5 years

**28%** at 10 years

Mostly deep disease; several reasons for repeat procedures.

PATIENT MESSAGE **Most did not have repeat surgery during follow-up; risk rises over time.**

Lemos 2026 • Roman 2023 14

14

## The plan after surgery matters

If you are not trying to conceive now, discuss hormonal suppression.

**Can lower recurrence**

Hormonal treatment can help reduce the chance of disease returning.

**Options to discuss**

A hormonal pill, progestogen or hormonal IUD, when suitable.

**Not for immediate conception**

Suppression is not prescribed to improve pregnancy while trying to conceive.

PATIENT MESSAGE **Aftercare should fit your pregnancy plans and medication preferences.**

Zakhari 2021 • ESHRE 2022 • Lemos 2026 15

15

## Five questions for your surgeon

Shared decisions begin before the consent form.

**1–2 Goals & alternatives**

What do we hope to improve? What other options fit my goals?

**3–4 Procedure & risks**

What will you remove? What are my risks and your team’s experience?

**5 Aftercare**

What is the recovery, fertility and follow-up plan if symptoms remain?

PATIENT MESSAGE **You deserve a clear plan before—and after—the operation.**

ESHRE 2022 16

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@joneinarssonmd | www.gynsurgery.is

## Your goals. Your choices. Your plan.

**Surgery can help**

Especially when the procedure matches the disease and your goals.

**No guaranteed cure**

Pain relief, fertility and long-term outcomes vary.

**Care continues**

Protect ovaries, weigh risks and build an aftercare plan.

Thank you • Questions

PATIENT MESSAGE **You are a partner in every decision.**

ESHRE 2022 17

17

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PATIENT MESSAGE **These sources explain the evidence—and its limits.**

19

18

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PATIENT MESSAGE **These sources explain the evidence—and its limits.**



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# Endometriosis Across the Lifespan: *Adolescence to Menopause*

Michelle Louie, MD, MS · Mayo Clinic
Asha McClurg, MD, MS · University of North Carolina

NOVEMBER 13-16, 2026 · BOSTON · #AAGL26

1

## Disclosures

- Michelle Louie is a consultant for Hologic Inc. and receives personal consultancy fees
- Asha McClurg has no disclosures

2

## Objectives

- Describe how endometriosis symptoms, treatment options, and priorities evolve across different life stages
- Identify patient-centered goals and outcomes that should guide individualized endometriosis treatment decisions.
- Apply practical strategies to engage in informed, shared decision-making, using life-stage–specific considerations to align treatment choices with personal values and long-term goals.

Adolescence → 20s-30s → 40s-50s → Menopause

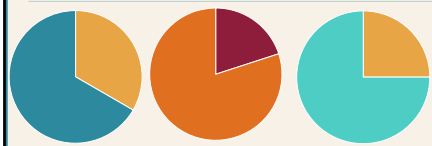
3

## Teenagers



4

## Diagnosis



2/3 of adults with endometriosis report teenage symptom onset

1/5 reported symptoms before age 15

Laparoscopy positive in 60-75% of teenagers

- Barriers to diagnosis: Teens, Family, Doctors



1. Shim JY et al. *Obstetrics & Gynecology*, *143*(1), 44–51.
2. Ballweg ML. J Pediatr Adolesc Gynecol 2003;16:S21–6.
3. Janssen EB et al. Hum Reprod Update 2013;19:570–82.

5

## Work up

- Presenting symptoms: AUB, dysmenorrhea, pelvic pain- cyclic and non-cyclic
  - Cyclic + Acyclic pelvic pain in 62%,
  - Dysmenorrhea alone in <10% of pts
- Eval for co-morbid conditions
- Patient centered approach to exam
- Ultrasound to rule out other etiologies of pelvic pain, dysmenorrhea
  - Obstructive anomalies increase risk of endometriosis
  - Discuss ultrasound route



1. Shim JY et al. *Obstetrics & Gynecology*, *143*(1), 44–51.
2. Kapczuk K et al. J Clin Med 2023;12:2007.
3. Laufer MR et al.J Pediatr Adolesc Gynecol 1997;10:195–202.

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## Treatment

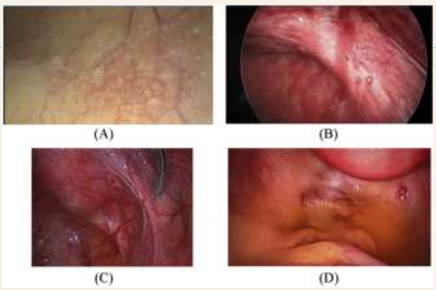
- Hormonal suppression:
  - First line
    - Combined hormonal therapy (pill, patch, ring)
    - Progestin only therapy (pill, shot, IUD-52mg!, implant)
  - Second line
    - GnRH agonist + add back, GnRH antagonist, Danazol



1. Shim JY et al. *Obstetrics & Gynecology*, *143*(1), 44–51.
2. Tyson N et al. JMIG, 2024; 31, 378-386

7

## Surgery




8




9

## Planning Future Fertility

- Live birth rates remain 10–15% lower for patients with endometriosis
- Oocyte vitrification counseling especially for high risk:
  - Age >30
  - Low ovarian reserve
  - Ovarian endometrioma
  - Recurrent endometriosis/previous surgery



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## Indications for surgery

- Symptom management
- Confirmation of diagnosis
- Dysmenorrhea with unexplained infertility
- Exclusion of malignancy
- Organ dysfunction
- Deep endometriosis
- Surgery for fertility optimization alone controversial

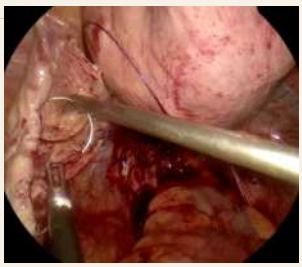


1. European Society of Human Reproduction and Embryology (ESHRE) Guideline Development Group. 2022.
2. Practice Committee of the American Society for Reproductive Medicine. *Fertil Steril.* 2012;98(3):591-598.
3. National Institute for Health and Care Excellence (NICE). NICE Guideline NG73. 2017

11

## Surgical Considerations

- Cystectomy has better symptom relief and lower risk of recurrence compared to drainage, but negative impact on ovarian reserve
  - Avoid electrosurgery
    - Hemostatic agents (e.g. ORC)
    - Suture closure
  - Consider adhesion barrier
- Avoid oopheropexy

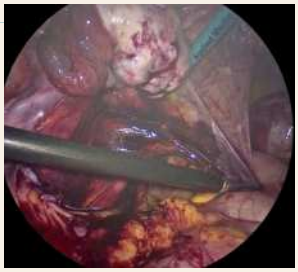


1. European Society of Human Reproduction and Embryology (ESHRE) Guideline Development Group. ESHRE guideline: Endometriosis. ESHRE; 2022.
2. Practice Committee of the American Society for Reproductive Medicine. Endometriosis and infertility: a committee opinion. Fertil Steril. 2012;98(3):591-598.
3. Shaltout MF, et al. J Ovarian Res. 2019 Jul 20;12(1):66.

12

## Surgical Considerations

- Consider concurrent chromopertubation, hysteroscopy
- Consider peritonectomy for:
  - Unexplained infertility
  - RIF/RPL
  - Positive ReceptivaDx® testing
  - Multifocal disease
- Repeat surgery is harmful to ovarian reserve, especially for recurrent endometrioma




1. McKee D, et al. J Gyn Surg. 2023;39(5). doi.org/10.1089/gyn.2023.0032
2. European Society of Human Reproduction and Embryology (ESHRE) Guideline Development Group. ESHRE guideline: Endometriosis. ESHRE; 2022.
3. Practice Committee of the American Society for Reproductive Medicine. Endometriosis and infertility: a committee opinion. Fertil Steril. 2012;98(3):591-598.


13

## Planning Future Fertility

- Hormonal suppression reduces recurrence after conservative surgery (versus placebo or expectant management), SRR 0.41-RR 0.30
  - Without postoperative hormones, endometrioma recurrence ~27% by 24 months
  - Long-term treatment; relapse rises after stopping
  - No best agent; most evidence for Dienogest, LNG-IUS, and continuous OCPs




1. Gniadek, Magdalena, et al. *Journal of Clinical Medicine*, vol. 15, 2026, https://doi.org/10.3390/jcm15114297.
2. Zakhari, A., et al. *Human Reproduction Update*, vol. 27, 2020, pp. 96 - 107, https://doi.org/10.1093/humupd/dmaa033.
3. Vercellini, P., et al. *Reproductive biomedicine online*, vol. 21 2, 2010, pp. 259-65, https://doi.org/10.1016/j.rbmo.2010.04.018.
4. Veth, V., et al. *Fertility and sterility*, 2024, https://doi.org/10.1016/j.fertnstert.2024.07.033.


14

## Actively Trying to Conceive

- Symptom management with non-hormonal medications and lifestyle changes.
- Hormone medication not effective for improving natural fertility (e.g if patient actively trying to conceive in <3 months after surgery)
- REI Referral:
  - >6 months of trying to conceive
  - Age over 35
  - Other infertility factors (e.g. PCOS, tubal, male factor)
  - Low AMH/AFC
  - Low Endometriosis Fertility Index (EFI)


1. Dunselman, G., et al. *Human reproduction*, vol. 29 3, 2014, pp. 400-12, https://doi.org/10.1093/humrep/det457.
2. Vatsa, R., and A. Sethi. *Middle East Fertility Society Journal*, vol. 26, 2021, https://doi.org/10.1186/s43043-021-00082-3.
3. Zwierzchowska, Maria, et al. *Quality in Sport*, 2024, https://doi.org/10.12775/qs.2024.25.56839.


15




16



**30s-40s**

17

## What are her goals?

- Fertility?
- Complete with childbearing?
- Symptom stability?
- Burden of re-intervention?
- How can we optimize her quality of life?



18

## Medical Management

**Adjust therapy**
- Continue regimen if tolerating well
- Consider progestin only for pts
> 35 with MI, stroke or VTE risk factors
- Shorter interval IUD replacement

**Non hormonal therapies**
- Mental health > CBT, Mindfulness, yoga
- Exercise and pelvic floor PT
- Low fat, high fiber diet



1. Carey, E. T. *Obstetrics & Gynecology*, *146*(3), 323–340.

19

## Surgical Management

**Role of Hysterectomy**
- Hysterectomy not a cure, but can have long term pain improvement
- Total > supracervical
- 40% of pt with adenomyosis have DIE
- Hysterectomy alone associated with elevated CV risk

**Role of oophorectomy**
- Reserve for treatment failure <45
- HRT if early age of surgical menopause



1. Carey, E. T. *Obstetrics & Gynecology*, *146*(3), 323–340.
2. Kho, K. A et al. *Obstetrics & Gynecology 2026*
3. Laughlin-Tommaso SK. Menopause 2018;25:483–92.

20



**Menopause**

21

## Endometriosis after Menopause: Pathophysiology

- Local estrogen biosynthesis within lesions via aromatase P450
- Peripheral aromatization of androgens (estrone) in adipose tissue and skin
- Exogenous hormones or endogenous threshold shifts
- Genetic-epigenetic incidents induce estrogen-independent growth
- Coelomic metaplasia of peritoneal mesothelium permits de novo lesion formation



1. Ladanyi, C., et al. *Current Opinion in Obstetrics & Gynecology*, 2019, https://doi.org/10.1097/gco.0000000000000548.
2. Secosan, Cristina, et al. *Diagnostics*, vol. 10, 2020, https://doi.org/10.3390/diagnostics10030134.
3. De Almeida Asencio, Fernanda, et al. *Gynecological Surgery*, vol. 16, 2019, pp. 1-11, https://doi.org/10.1186/s10397-019-1056-x.
4. Lamceva, Ielizaveta, et al. *International Journal of Molecular Sciences*, vol. 24, 2023, https://doi.org/10.3390/ijms24054254.

22

## Endometriosis after Menopause: Prevalence

- Prevalence estimated to be 2-5%
- True prevalence likely underestimated due to underdiagnosis/misdiagnosis
  - Incidental detection
  - Atypical presentation
  - Population bias
  - New versus persistent disease



1. Secosan, Cristina, et al. *Diagnostics*, vol. 10, 2020, https://doi.org/10.3390/diagnostics10030134.
2. Inceboz, U. *Women's Health*, vol. 11, 2015, pp. 711 - 715, https://doi.org/10.2217/whe.15.59.
3. Rahaem, M., et al. *Journal of Clinical Medicine*, vol. 14, 2025, https://doi.org/10.3390/jcm14228067.

23

## Hormone Replacement Therapy

- HRT should not be denied solely due to endometriosis history, particularly in premature menopause where benefits outweigh risks
- Optimal route, dosage, timing not known
- Women with residual disease after surgery have increased recurrence risk
- Continuous combined HRT is recommended over estrogen-only therapy
  - Unopposed estrogen is associated with higher risk of recurrence and malignant transformation (e.g. ovarian cancer, HR 2.90)



1. Moen, M., et al. *Maturitas*, vol. 67 1, 2010, pp. 94-7, https://doi.org/10.1016/j.maturitas.2010.04.018.
2. Amer, S., and S. Bazmi. *Journal of Clinical Medicine*, vol. 12, 2023, https://doi.org/10.3390/jcm12010336.
3. Lee, Hee Joong, et al. *Cancers*, vol. 15, 2023, https://doi.org/10.3390/cancers15061708.

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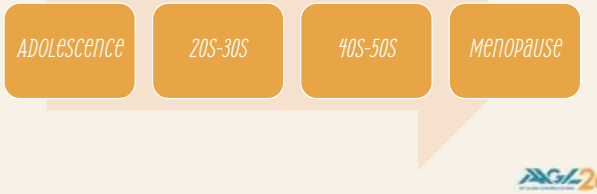
## Cancer Risk

- **Ovarian cancer**: SRR 1.3-1.93, particularly clear cell (SRR 3.44) and endometrioid (SRR 2.33) histotypes (not serous)
  - Deep endometriosis and/or ovarian endometriomas carry highest ovarian cancer risk (aHR 9.66), while superficial peritoneal disease shows no significant excess
  - Overall survival is significantly better (HR 0.48); lower recurrence and mortality rates
- **Endometrial cancer**: RR 1.35-1.66, likely due to detection bias
- **Cervical cancer**: SRR 0.68, likely due to surveillance/hysterectomy bias
- ***Current evidence does not justify routine oncologic surveillance or prophylactic surgery solely based on an endometriosis diagnosis***
  - Absolute lifetime risk of ovarian cancer in women with endometriosis, <2–5%
  - Women at highest risk may benefit from targeted counseling


1. Kvaskoff, M., et al. *Human reproduction*, 2020, https://doi.org/10.1093/humupd/dmaa045.
2. Bogani, G., et al. *Gynecologic oncology*, vol. 209, 2026, pp. 88-98, https://doi.org/10.1016/j.ygyno.2026.05.004.
3. Barnard, M., et al. *JAMA*, 2024, https://doi.org/10.1001/jama.2024.9210.


25

## Endometriosis across the lifespan:




26

# Thank you!

27

# Beyond Surgery: Lifestyle Adjuncts What the Evidence Actually Says & What Doesn't Work

Leigh Ann Humphries, MD MSCE

University of California San Francisco
Center for Reproductive Health

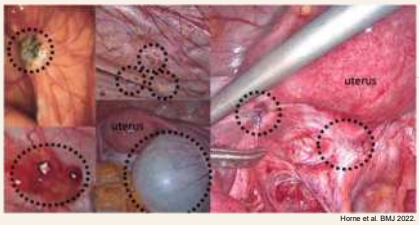
NOVEMBER 13-16, 2026 · BOSTON · #AAGL26

1

## Disclosure

- I have no financial relationships to disclose.

2




Horne et al. BMJ 2022.



**Beyond surgery and medications …**
**What else can I do?**

3










**"Balance your hormones"**

**"Detox"**

**"Reset your immune system"**




4




5

## The Evidence-Based Lifestyle Guide to Endometriosis:

- Mediterranean diet
- Limit alcohol / red meat intake

Next talk

- Physical activity & exercise
- Sleep hygiene
- Pelvic floor exercises
- Acupuncture
- Cognitive behavioral therapy & meditation

6

## 1. Move your body: Physical activity & exercise

- Modulate systemic inflammation
- Alter hormonal regulation
- Improve pain processing pathways
- Strengthen musculoskeletal & pelvic floor function

6 trials: improved QOL, pain with menstruation and sex, fatigue, anxiety/depression, sexual & GI function, sleep Benefits also from telehealth and virtual reality exercise; may continue for months after completion

**Specific interventions in endometriosis:**

**Hatha Yoga**
Focus on breath work, alignment, and flexibility



**Stretching/Aerobic/Resistance exercises**
Progressive increases in volume and intensity



Rodriguez-Ruiz et al. J Clin Med 2025
Goncalves et al. J Altern Comp 2017.
Arlacho-Cordon et al. Arch Phys Med 2023.
Salinas-Asensio et al. Eur J Ob Gyn 2025.
Xie et al. PLoS One 2025.

LIMITATIONS:
- Very small trials
- Diff interventions/outcomes
- Supervised intense programs
- Risk of bias

7

## 2. Practice good sleep hygiene: Quantity & quality of sleep

There is a strong, consistent observational link between endometriosis pain and worse sleep




Strategies identified in 30 studies of pts with chronic pain:
1. Pre-bed state: avoid anything that may alert you before bedtime
2. Exercise: avoid exercising to sweating within 1 hr of bed
3. Alcohol, tobacco, and caffeine: avoid within 4 hrs of bed
4. Sleep environment: optimize temperature, light, noise

**Specific interventions in endometriosis:**

**Melatonin**
- Fewer sleep disturbances
- Longer sleep duration
- Reduced chronic pain

Sumbodo et al. Eur J Ob Gyn Reprod 2024.
Facchin et al. RBMO 2021.
Esmaeilzadeh et al. PLoS One 2025.
Gupta et al. BMJ Open 2023.

LIMITATIONS:
- Only 1 trial focused on sleep as primary outcome

8

## 3. Relax & retrain the pelvic floor: Pelvic floor physical therapy

Addresses muscle hypertonia and both peripheral & central sensitization

- Significantly reduced chronic pelvic pain, pain with sex; improved quality of life
- Focus on relaxation and down-training (teaching overactive muscles to fully release/lengthen)
- Unclear benefit of at-home exercises vs. guided therapy

Rodriguez-Ruiz et al. J Clin Med 2025.
Del Forno et al. Ultrasound Ob Gyn 2021.
Gabrielsen et al. J Physiother 2025.






PelvicRehab.com.
American Urogynecologic Society, Patient Fact Sheets.
Hinge Health.

LIMITATIONS:
- Small sample sizes
- Often bundled with other interventions (e.g. exercise)
- Mixed results
- Short-term follow-up

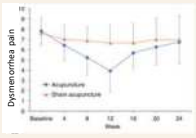
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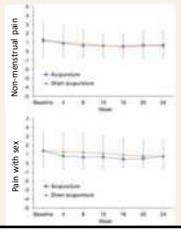
## 4. Use targeted stimulation: Acupuncture therapy

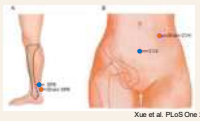
- Upregulate beta-endorphins
- Reduce prostaglandins
- Lower inflammation (TNF-α and IL-1)

Regimens ranged from weekly x 5 wks, twice weekly x 8 wks, three times weekly x 12 wks
- Reduced dysmenorrhea, pelvic pain, pain with sex, quality of life vs. sham
- Benefits may not be sustained after discontinuation
- Pain relief is not superior to medical therapy

Li et al. F&S 2023.
Wang et al. Comp Ther Med 2023.



Xue et al. PLoS One 2023.

LIMITATIONS:
- Small sample sizes
- Inconsistent regimens
- Difficult to adequately blind

10

## 5. Prioritize mental health: Cognitive behavioral therapy & mindfulness

- Improve mental health, mood, quality of life
- Reduced anxiety, depression, catastrophizing
- Direct effects on pain scores/intensity are more variable
- Effective in multiple formats: group therapy, individual, online

Key elements:
- Pain science education
- Cognitive restructuring
- Catastrophizing reduction
- Graded exposure/behavioral activation





Pino-Sedeño et al. Front Psychol 2024.
Chandra et al. Pain 2026.
Moreira et al. Eur J of Pain 2022.

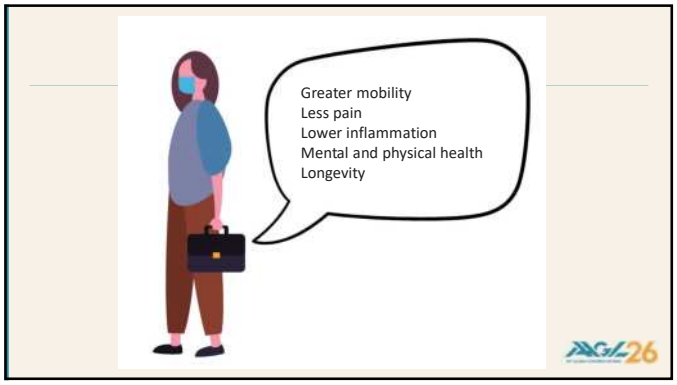
LIMITATIONS:
- Small sample sizes
- Inconsistent interventions / outcomes
- High risk of bias

11

## What is less likely to work…

- Highly restrictive or "fad" diets (risk of disordered eating)
- Salivary / urinary hormone panels
- Castor oil
- "Estrogen detox" protocols
- Endo influencer lifestyle packages

12




13

## References


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- Image references: PelvicRehab.com, HingeHealth.com, American Urogynecologic Society voicesforpfd.org
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14


Endometriosis, Nutrition & Inflammation:
From Evidence to Practice
Savannah Regensburger, MS, MBA, CNS
Board-Certified Clinical Nutritionist, Researcher, Speaker, & Women's Health Advocate

1


Why Endometriosis Nutrition?
Where My Story Began
Grew up in a small, rural town in Colorado
First period at 8 years old
Grew up an athlete (Softball was my first dream)

2


When Things Started To Change...
Chronic inflammation
Constant bloating and "UTIs"
Painful ovulations & periods
Excruciating pelvic and back pain

3


I Wanted to Know "Why"
Sixth Traumatic Brain Injury
B.S. Neuroscience
(Thesis Topic: Neuroplasticity)
M.S. Medical Nutrition
(Thesis Topic: Nutrition Through Menopause)
MCAT
Medical College Admission Test
Clinical Research
Next stop: Med school!

4


Except...
An unknown illness kept me from my dreams.
Celiac Disease
PMDD
Anxiety
Ankylosing Spondylitis
Interstitial Cystitis
"Normal part of being a woman"

5


In December 2024, at 28 years old, after years of symptoms, I was finally diagnosed with ENDOMETRIOSIS.
Endometriosis became the place where my neuroscience education, clinical nutrition work, research, and lived experience finally came together.

6

## Diagnosis is NOT the Finish Line

Receiving a "name for the pain" does not relieve it. For many, it marks the beginning of a lifelong journey with a disease that has no cure.

**NO CURE EXISTS**

A population-based cohort study of over 107,000 individuals found that mental health risk is elevated after diagnosis and peaks in the first year.

For patients, the reality of a chronic, incurable disease sets in immediately after diagnosis, often alongside the weight of years of medical dismissal and uncertainty about what comes next.

**Highest**
mental health risk in **year one after** endometriosis diagnosis

**105.3**
mental health events per **1,000 person-years** in the **endometriosis group** vs. **66.5** in **unexposed individuals**

**2.82x** higher risk for **anxiety** and **2.93x** for **depression** in women with endometriosis vs. the general population

Thiel PS et al. Am J Obstet Gynecol. 2024;230(6):649.e1-19 | Li W et al. Arch Med Sci. 2025;21(5):1985-96

7

## The "Endo Toolbox"

Surgery and beyond: a multimodal, real-life approach to endometriosis care

**Nutrition**
- Anti-inflammatory foods (Mediterranean-style, plant-forward pattern)
- Blood sugar stability
- Sustainable eating
- Targeted supplementation

**Sleep**
- Circadian alignment
- Deep sleep for immune repair
- Hormone regulation

**Nervous System Regulation**
- Vagus nerve support & vagal tone
- Meditation & grounding
- Reducing central sensitization

**Movement**
- Nervous system-supportive movement
- Strength training to preserve muscle mass
- Lymphatic support
- Movement that you enjoy




**Hydration**
- Electrolyte balance
- Bowel regularity
- Cellular function

**Social Health**
- Community & support
- Reducing isolation
- Advocacy & boundaries

**Adjunct & Integrative Therapies**
- Pelvic floor physical therapy
- Acupuncture
- Trauma-informed care

*You won't use every tool every day, it's about learning which combination supports you in each season, flare, or phase. The goal is not perfection, it's about doing your best (and your best is enough).*

8

## The "Endo Toolbox"

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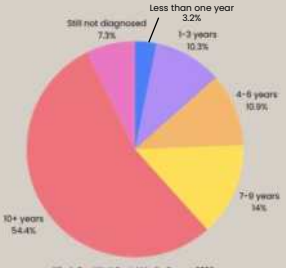
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*You won't use every tool every day, it's about learning which combination supports you in each season, flare, or phase. The goal is not perfection, it's about doing your best (and your best is enough).*

9

## Why The Toolbox Matters

**Approximately how many years passed between your first symptoms and diagnosis?**
(1300+ responses)

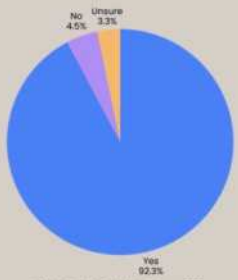



#EndoCantWait Social Media Survey, 2026.
Presented by Savannah Regensburger, Emma Kolach, & Bri Rubio

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## Why The Toolbox Matters

**Were you ever told your symptoms were "normal" or "just part of being a woman"?**

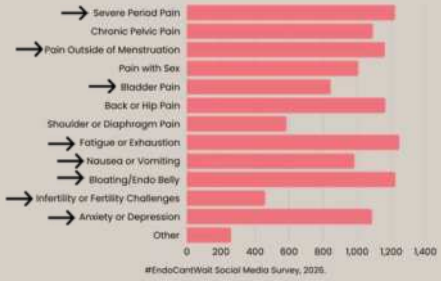



#EndoCantWait Social Media Survey, 2026.

11

## Why Nutrition Matters

**Which symptoms have you experienced?**




#EndoCantWait Social Media Survey, 2026.

12

## Nutrition in Endometriosis Is Also a Mental Health Conversation

*Yale University Research | JAMA Network Open, 2023*

**Genetic correlation with depression**

**Genetic correlation with anxiety**

**Genetic correlation with eating disorders**

The relationship between endometriosis and mental health extends beyond the psychological burden of chronic pain. Shared genetic factors may also contribute.

A shared genetic variant (**DGKB rs12666606**) was identified between **endometriosis and depression** and is highly expressed in both brain regions and female reproductive tissue.

Psychiatric symptoms in endometriosis should never be dismissed as simply a response to pain or used to invalidate a patient's physical symptoms.

Koller D et al. JAMA Netw Open. 2023;6(1):e2251214

13

## Eating Disorders and Disordered Eating in Endometriosis

*Why Nutrition Care Must be Trauma-Informed*

↑ **Mental Health Risk and Disordered Eating**
- Endometriosis is associated with higher rates of *depression, anxiety & eating disorders* (JAMA Network Open, 2023).
- Greater vulnerability to *disordered eating behaviors* & *clinically diagnosed eating disorders* (Arch Gynecol Obstet, 2026).

**Pain + Body Image**
- Emotional eating, binge tendencies & restrictive dieting are associated with *pain intensity and body image* (Arch Gynecol Obstet, 2026).

**Up to 62%**
- Among individuals with comorbid PCOS/PMOS, eating disorders were *3–6× more likely* compared with controls (Adv Nutr, 2024).

**66%**
- Reported altering their diet after diagnosis, reflecting both adaptive and potentially maladaptive responses to symptoms (Front Nutr, 2023).

**When we recommend dietary change, we must consider the patient's relationship with food, pain, body image, and restriction.**

Koller D et al. JAMA Netw Open. 2023;6(1):e2251214 | Di Michele S et al. Arch Gynecol Obstet. 2026;313(1):58 | Mazza E et al. Front Nutr. 2023;10:1273978 | Lalonde-Bester S et al. Adv Nutr. 2024;15(4):100193

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## Why Diet Matters & The Inflammatory Cycle

Endometriosis is an estrogen-dependent, inflammatory disease. Lesions produce prostaglandins ($PGE_2$) and inflammatory cytokines (IL-6, TNF-α, IL-1β).

Lesions → prostaglandins + cytokines → oxidative stress → more inflammation → local estrogen production → lesion growth

**Where Anti-Inflammatory Nutrition Fits:**
- Antioxidant-rich foods may help buffer oxidative stress
- Fiber and the gut microbiome *may* influence estrogen clearance (emerging)
- Mediterranean-style, plant-forward pattern for whole-body health

**Bottom line:**
Nutrition doesn't remove lesions. The goal is to support the inflammatory environment around them.

Bulun SE et al. Endometriosis. Endocrine Reviews, 2019.

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## Anti-Inflammatory Nutrition

Nutrition is not a cure; it is foundational support. Small, sustainable shifts may support inflammation, metabolic and gut health over the long term.

**Blood Sugar & Metabolic Health**
- Pair protein + fiber + healthy fats at meals
- Supports more stable postprandial glucose
- Supports insulin sensitivity and metabolic health

**Adequate Protein**
- Supports preservation of lean mass
- Supports immune function
- Provides amino acids needed for tissue repair

**The 80/20 Approach**
- 80% anti-inflammatory, whole-food foundation
- 20% flexibility for real life
- Sustainability > restriction
- Progress > perfection

**Fiber, Gut Health & Estrogen Metabolism**
- Improves bowel regularity
- Feeds beneficial gut bacteria
- The estrobolome (gut bacteria involved in estrogen metabolism) is a biologically interesting, emerging area

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## A Practical Default: Mediterranean-Style Eating

**No specific diet has been established as an effective treatment for endometriosis, and overly restrictive diets can carry nutritional and psychological downsides.**

*Flexible pattern → Emphasize whole foods → Individualize to symptoms → Reassess*

### WHAT IT LOOKS LIKE

- **PLANT-FORWARD**
  Vegetables, fruits, legumes + whole grains
- **FISH + LEAN PROTEINS**
  In place of red + processed meat
- **OLIVE OIL, NUTS + SEEDS**
  As the main fats
- **MINIMALLY PROCESSED**
  Fewer ultra-processed foods
- **WHOLE-BODY HEALTH**
  Supports heart, metabolic, gut + bone health

### WHAT THE TRIAL SHOWED

**Randomized controlled trial · 140 patients · 12 months**
Symptomatic endometriosis despite hormonal therapy
Mediterranean diet + aerobic exercise coaching vs. usual care

| OUTCOME | COACHING | CONTROL |
|---|---|---|
| Non-menstrual pelvic pain (0–10 scale) | −1.6 | −0.7 |
| Dyschezia (painful bowel movements) | −0.9 | 0.0 |
| Reported improved overall health | 47% | 27% |

Anxiety also improved. Depression and quality-of-life scores did not change significantly.

**A flexible, sustainable pattern rather than a restrictive one. Diet + exercise were combined, so their individual effects can't be separated. Lifestyle care may complement, not replace, medical treatment.**

*Barut MC. Clin Nutr ESPEN. 2026;72:102954 | Donati A et al. Eur J Obstet Gynecol Reprod Biol. 2026;326:115381*

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## The Foundations

*Most of this evidence is observational and relates to endometriosis risk, not to treating established disease.*

### FIBER
GUT HEALTH & HORMONE METABOLISM



**~95% of Americans fall short of fiber recommendations.**

Average intake is ~15 g/day, compared with recommended intakes of ~25 g/day for women and 38 g/day for men.

**Higher fruit intake was associated with lower endometriosis risk.**

In the Nurses' Health Study II, ≥1 serving of citrus/day was associated with a 22% lower risk compared with <1 serving/week.

Supports bowel regularity and gut microbiome diversity.

Quaglani & Fett-Gunderson, 2017; Harrison et al., Human Reproduction, 2018.

### CARBOHYDRATES
FIBER-RICH, WHOLE-FOOD SOURCES



**Carbohydrate quality matters.**

Prioritize fiber-rich, minimally processed carbohydrate sources including whole grains, legumes, fruits, vegetables, and starchy vegetables.

Whole-food carbohydrate sources provide fiber, micronutrients, polyphenols, and other bioactive compounds that support overall metabolic and gut health.

Current evidence does not support broadly eliminating carbohydrates as an endometriosis treatment.

**Think carbohydrate quality, not carbohydrate avoidance.**

### FATS
INFLAMMATION & CELLULAR HEALTH



**The type of fat may matter more than total fat.**

In the Nurses' Health Study II:

- Highest vs. lowest trans-fat intake was associated with a 48% higher risk of endometriosis.
- Highest vs. lowest long-chain omega-3 intake was associated with a 22% lower risk.

Total fat intake itself was not associated with endometriosis risk.

Missmer et al., Human Reproduction, 2010.

### PROTEIN
TISSUE REPAIR, IMMUNE FUNCTION & SATIETY



**Prioritize lean, minimally processed protein sources.**

Fish, poultry, eggs, legumes, nuts and seeds provide high-quality protein and important nutrients.

**One study found higher endometriosis risk with greater red and processed meat intake.** Replacing red meat with poultry, fish, shellfish, or eggs was associated with lower risk.

**Red meat and the gut**

Red meat is linked to gut inflammation and colitis risk, but no study has tested cutting it in endometriosis. Many patients report it worsens bloating and "endo belly."

Yamamoto et al., AJOG, 2018; Dangt et al., J Crohns Colitis, 2020; Cassi et al., Gut, 2016.

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## Common Questions & What You May Have Heard Online

*No specific diet has been established as an effective treatment for endometriosis, and overly restrictive diets carry nutritional and psychological risks.*

| Claim | What the evidence says |
|---|---|
| "Sugar feeds endo" | No clinical evidence. Limiting added sugar is good general advice, not an endo treatment. |
| Coffee/caffeine | Usual intake not shown to worsen endo. Very high intake (>300 mg/day) is modestly associated with risk in some observational data. |
| Chocolate | No endo-specific evidence for avoiding it. Individual triggers vary. |
| Alcohol | Possible association with risk, but no evidence that abstaining treats disease or reduces lesions. |
| Soy/phytoestrogens | Human evidence is limited and inconsistent. No good evidence for routine avoidance. |
| Seed oils, keto, carnivore | No endo-specific clinical evidence supports these as treatment. |

*Kechagias KS et al. Nutrients. 2021 | Li Piani L et al. Sci Rep. 2022 | Banaut MC. Clin Nutr ESPEN. 2026.*

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## Therapeutic Elimination Diets

**Reduce → Reintroduce → Identify triggers → Personalize**

*Temporary restriction should answer a clinical question rather than create a permanent list of "bad foods."*

### GLUTEN + DAIRY

**Commonly eliminated, though evidence does not support routine avoidance. However, many patients report improvement in GI symptoms with reduction or elimination.**

If tolerated, Greek yogurt, kefir and harder cheeses can add protein and calcium; however, lactose, fermentation and histamine tolerance may still affect symptoms.

Some patients report less bloating, distension or GI discomfort when reducing gluten-containing foods. This may reflect lower fructan/FODMAP exposure or fewer highly processed carbohydrate foods, not necessarily gluten itself.

**Screen for celiac disease while gluten is still being consumed.**

### LOW-FODMAP

**FODMAPs:** poorly absorbed, fermentable carbs that can drive gas, bloating, pain and altered bowel habits.

**Fructans** (wheat, garlic, onion): may explain some perceived "gluten" sensitivity
**Lactose** (milk, soft cheese): may explain some perceived "dairy" sensitivity
**GOS** (beans, lentils) · **Polyols** (stone fruit, mushrooms, sweeteners)

**EndoFOD RCT (2025):**
- 28-day low-FODMAP vs. control diet in women with endo and GI symptoms
- **60% vs. 26%** responded, with less pain and bloating and better quality of life.

*For GI symptom management, not endometriosis treatment. Use short term, then reintroduce.*

### SIBO / IMO + GI OVERLAP

**Treat the driver, not just the food.**

In a 2025 case-control study, **91.9%** of endometriosis patients tested positive for SIBO or methane overgrowth (IMO), compared with **83.1%** of symptomatic controls.

Potential contributors to recurrent symptoms include altered motility, bowel involvement, adhesions, prior pelvic surgery, methane-associated slow transit and motility-slowing medications.

**Recurrent SIBO/IMO → look for the underlying driver.**

### LOW-HISTAMINE

**Potentially useful in select symptomatic patients; evidence remains limited.**

There is no universally accepted food list, diagnostic standard or endometriosis-specific dietary evidence.

Fermented foods, which are typically high in histamines, are commonly restricted. This matters because foods often promoted for gut health, including kefir and other fermented foods, may not be tolerated by every patient.

**If suspected: short-term reduction → symptom assessment → systematic reintroduction.**

*Marzati et al., 2012; Skodje et al., Gastroenterology, 2018; Ulven et al., Adv Nutr, 2019 | Varney JE et al. Aliment Pharmacol Ther. 2021;61(12):1889-1903 | Moore et al., Austin J Obstet Gynaecol, 2017 | Halton P, et al. Int J Gynaecol Obstet. 2025;170:284-291. | Comas-Basté et al., Nutrients, 2020/2021*

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## Supplements

**Several supplements have been studied, but the evidence remains limited, and none are currently established as routine treatments for endometriosis.**

*Test when appropriate → Identify the indication → Correct deficiencies → Reassess*

### STUDIED IN ENDOMETRIOSIS

| SUPPLEMENT | EVIDENCE |
|---|---|
| Vitamin D | ~31% of U.S. women are deficient. Levels are lower in endo and in more severe disease. Adolescent RCT: no pain benefit vs. placebo. Correct deficiency. |
| Vitamins C + E | Small RCT: reduced pelvic pain and inflammatory markers. |
| Melatonin | Phase II RCT: reduced pain. |
| NAC | Observational: reduced pain and endometrioma size. |
| Curcumin | Alone: no benefit. Added to dienogest: reduced pain. |
| Omega-3 | Adolescent RCT: not significant vs. placebo. |
| Probiotics (L. gasseri) | Small RCT: reduced dysmenorrhea. |

### SYMPTOM SUPPORT

**Magnesium glycinate** Sleep
RCT: modest improvement in insomnia.

**Magnesium citrate** Bowel regularity
Osmotic laxative; magnesium RCTs improved chronic constipation.

**Ginger** Period pain
Meta-analysis: reduced dysmenorrhea pain.

### POPULAR ONLINE

*Interesting lab data, but no human endometriosis trials.*

Green tea (EGCG) · DIM · ALA
B6 · Glutathione

*ASH, Blood Adv, 2026 | Fischer et al., 2023 | Liu et al., 2018 | Qiu et al., 2020 | Nodler et al., 2020 | Santanam et al., 2013 | Schwertner et al., 2013 | Porpora et al., 2013 | Anastasi et al., 2023 | Gudarzi et al., 2024 | Sargsyan-Taghazi et al., 2025 | Itoh et al., 2011 | Mendes da Silva et al., 2017 | Schuster et al., 2025 | Mori et al., 2019 | Moafeghinia et al., 2024*

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## New Ferritin Guidelines

### 2026 ASH DIAGNOSTIC THRESHOLDS

Ferritin thresholds for iron deficiency

| | |
|---|---|
| ≤30 ng/mL | **Ferritin** in menstruating adults |
| ≤50 ng/mL | **Ferritin** with heavy menstrual bleeding |
| <100 ng/mL or TSAT <20% | **Ferritin or transferrin saturation (TSAT)** when inflammation is present |

The new guidance moves away from relying on the older ~15 ng/mL cutoff in menstruating individuals.

### IF SUPPLEMENTING IRON

**Iron bisglycinate**
Often better tolerated, with fewer GI side effects.

**Vitamin C**
May enhance absorption from a supplement or vitamin C–rich food.

**Alternate-day dosing**
May improve fractional iron absorption and can improve tolerability.

**Heavy menstrual bleeding and chronic inflammation can make iron deficiency easy to miss.**

*ASH Guidelines, Blood Advances, 2026 | Stoffel NU et al., Haematologica, 2020.*

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## Food Security & Real-Life Barriers

**Nutrition recommendations only work when they are accessible.**

Cost, food access, time, energy, disability, cooking capacity, and cultural preferences all shape what is realistic for a patient.

COST · ACCESS · TIME · ENERGY · CAPACITY




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## The Future of Endometriosis Care is Multidisciplinary

Surgery can change a life, but it should not have to carry the entire burden of care. When we treat the whole person, we give patients more of their lives back.

**Thank you** for being part of changing what endometriosis care looks like!



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# When the Calendar Predicts Pain: Breaking the Cycle of Anticipation, Anxiety, and Endometriosis

Lori B. Waxenberg, PhD, ABBP · University of Florida

NOVEMBER 13-16, 2026 · BOSTON · #AAGL26

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## Disclosure

*I have no financial relationships to disclose.*

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## Objectives

*Explain the neuroscience of anticipatory anxiety of pain*

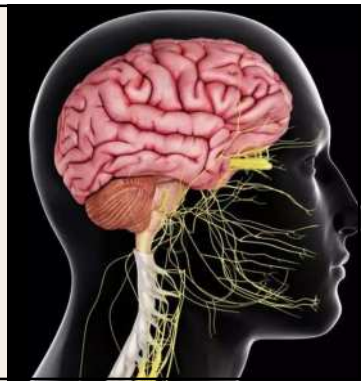
*Discuss the impact of central nervous system activation on quality of life*

*Describe strategies to break the anticipatory anxiety cycle*

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**Endometriosis is more than pelvic lesions**

*Pain is produced by the nervous system, not just the pelvis*



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**How the calendar becomes a trigger**

The Brain is a prediction machine.

Its job is survival.

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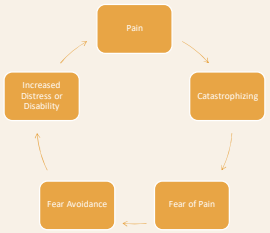
**How the calendar becomes a trigger**

*- It's all about protection*




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## Anticipatory anxiety




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## The Neuroscience of Anticipation

- The two components of pain:
- Sensory – how intense is the pain?
- Emotional – how threatening is the pain?

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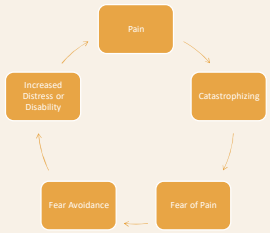
**Hidden costs**

**Endometriosis can shrink lives before it increases symptoms**



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## Anticipatory anxiety




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## Break the cycle

- Calm the nervous system
- Recognize it is trying to protect you and recognize that you are okay
  - Deep breathing, relaxation
  - Mindfulness
  - Identify negative thought patterns and find a balance
  - Creating a calming mantra



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## Break the cycle



- Reclaim activities
  - Don't let the calendar become your life planner
- Increase predictability
  - Uncertainty fuels anxiety
- Build Psychological Flexibility
  - Live a value driven life

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## Breaking the cycle

- For Providers:
- **Validation** lowers the threat.
- Use a **comprehensive** approach
  - Treat both the disease and pain processing



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## Resources

- **Relaxation and Stress Reduction Workbook**
  Martha Davis, Ph.D., Elizabeth Robbins Eshelman, M.S.W., Matthew McKay, Ph.D.
- **The Happiness Trap: How to Stop Struggling and Start Living: A Guide to ACT**
  Russ Harris, Ph.D.
- **Managing Pain Before It Manages You**
  Margaret Caudill, M.D., Ph.D.
- **Mind Over Mood: Change How You Feel by Changing the Way You Think**
  Dennis Greenberger, Ph.D. & Christine Padesky, Ph.D.
- **Quiet Your Mind and get to Sleep: Solutions to Insomnia for those with Depression, Anxiety or Chronic Pain**
  Colleen E. Carney, Ph.D. and Rachel Manber, Ph.D.

- Pain Coach - https://mobile.va.gov/app/pain-coach
- Insight timer - https://insighttimer.com/
- Breethe - https://breethe.com/
- Headspace - https://www.headspace.com/
- Calm - https://www.calm.com/
- Mood Mission - https://moodmission.com/

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## Takeaways

- Endometrioses pain is real and multifactorial.
- The brain learns patterns and can begin predicting pain.
- Anticipation and anxiety can amplify suffering.
- You can break the cycle by calming the nervous system and engaging in life.
- Providers can help break the cycle through validation and integrated care.



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*Why Surgery Isn't Enough?*
*Persistent Pain after Treatment*
*CENTRAL SENSITIZATION*


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## Disclosure - Jorge F. Carrillo, MD, MHPE, FACOG, PPSD

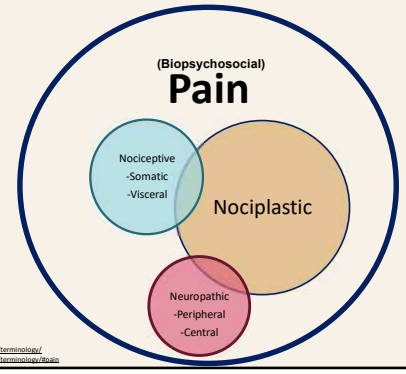
- The opinions expressed do not necessarily reflect those of the VA, U.S. Government, or any of its agencies
- Speakers Bureau: Vertex pharmaceuticals

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## Objectives

- Define nociplastic pain, central sensitization and chronic overlapping pain conditions
- Describe how to clinically suspect central sensitization
- List tools available to link sensitization with endometriosis
- Explain the clinical impact of identifying sensitization in those with endometriosis
- Review different treatment modalities

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https://www.iasp-pain.org/resources/terminology/
https://www.iasp-pain.org/resources/terminology/#pain

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**Nociplastic pain**

**Pain** that arises from altered nociception **despite no clear evidence of actual or threatened tissue damage** causing the activation of peripheral nociceptors, **or evidence for disease or lesion of the somatosensory** system causing the pain.

Patients can have both nociceptive and nociplastic pain

**Proposed in 2016**
No obvious activation of nociceptors/neuropathy, with clinical/psychological findings suggesting altered nociception

Pain arising from the altered function of pain pathways in periphery/CNS **causing increased sensitivity**

Applicable to to chronic primary pain conditions (CP in 1 or more anatomic regions + associated emotional distress/disability that cannot be better explained by another chronic pain condition)
- Chronic widespread pain
- Complex regional pain syndrome
- Chronic primary HA and orofacial pain
- Chronic primary visceral pain
- Chronic primary musculoskeletal pain

https://www.iasp-pain.org/resources/terminology/
Fitzcharles MA, Cohen SP, Clauw DJ, Littlejohn G, Usui C, Häuser W. Nociplastic pain: towards an understanding of prevalent pain conditions. Lancet. 2021;397(10289):2098-2110. doi:10.1016/S0140-6736(21)00392-5

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## Central Sensitization and prognosis

Might be useful in determining whether a favorable patient outcome is likely – persistence of pain after treatment - (useful in msk patients, osteoarthritis)

Preop features of CS predict a **poor outcome after surgery –increase hospital stay, poor quality of life, worse functional disability, greater dissatisfaction**- (total knee and hip arthroplasty, back surgery)

Multimodal analgesia –paracetamol, gabapentin, celecoxib to reduce opioid use

Zheng P, Zhang W, Leng J, Leng J. Research on central sensitization of endometriosis-associated pain: a systematic review of the literature. J Pain Res. 2019 May 8;12:1447-1456. doi: 10.2147/JPR.S199367. PMID: 31190961; PMCID: PMC6514295.
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Orr, N. L., Wahl, K. J., Lisonek, M., Acevedo, A., Noga, H., Albert, A., Bedaiwy, M. A., Williams, C., Allaire, C., & Yong, P. J. (2022). Central sensitization inventory in endometriosis. Pain, 166(1), e109–e120. https://doi.org/10.1097/j.pain.0000000000002351

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## CSI





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## Evidence on Central sensitization and Endometriosis Pain

CSI>= 40 may be helpful to identify patients with endometriosis with pain contributors related to CS

Higher CSI scores at baseline can be associated with worse pain outcomes after endometriosis surgery

CSI to counsel patients with endometriosis on expected outcomes of surgery

Multimodal/interdisciplinary approach (non-pharmacologic, pharmacologic, ERAS). ATC, anticonvulsants (gabapentin, pregabalin), NSRI's (duloxetine, venlafaxine)

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## Suspect Central Sensitization When…

*Convergences PP clinical criteria for chronic pelvic and perineal pain*

**Widespread pain**
Pain at multiple sites in the body

**Multiple pain diagnoses**
Overlapping IBS, bladder pain, fibromyalgia

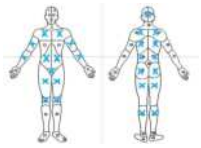
**Hyperalgesia / allodynia**
Pain out of proportion, or from light touch

**Opioid nonresponse**
Opioids fail to reduce the pain

**Peripheral therapies fail**
Pain persists despite local or surgical treatment

**Psychological distress**
Linked to anxiety, depression or distress

Patient intake body map



**Red flag on the intake body map:** pain marked across many regions, not just the pelvis

Levesque A, Riant T, Ploteau S, Rigaud J, Labat JJ; Convergences PP Network. Clinical criteria of central sensitization in chronic pelvic and perineal pain (Convergences PP Criteria): elaboration of a clinical evaluation tool based on formal expert consensus. Pain Med. 2018;19(10):2009-2015. doi:10.1093/pm/pny030

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**CENTRAL SENSITIZATION IN 60 SECONDS**




ACCESS VIDEO HERE

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## Treating Central Sensitization in Endometriosis

*Excising lesions does not reverse a sensitized nervous system: treat the nociplastic component directly*

**Phenotype first**
- CSI (≥40 = high sensitizer), QST and exam to detect the nociplastic component[1,2]
- High preoperative CSI predicts persistent pain after surgery[2]

**Educate and move**
- Pain neuroscience education to reframe pain and reduce threat[5,6]
- Graded exercise and pelvic physiotherapy as first-line care[3,6]

**Retrain the brain**
- CBT, ACT, mindfulness and pain reprocessing therapy[4]
- Screen for trauma and use trauma-informed psychological care[4]

**Centrally acting drugs**
- Adjuncts, not stand-alone: TCAs, SNRIs, gabapentinoids[3]
- Duloxetine + pregabalin combination may add benefit[5]

**Bottom line:** multimodal, non-pharmacologic care first; medications as adjuncts. Endometriosis-specific treatment trials are still lacking.


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## Conclusion

- CS is an underlying mechanism of nociplastic pain, whereas nociplastic pain is a pain phenotype
- Central Sensitization should be considered when person has pain at multiple sites, hyperalgesia/allodynia, pain that does not respond to peripheral therapies
- In those with endometriosis and central sensitization (CSI >40), decrease the GAIN (BRAIN), before performing a surgical intervention
- Patient education is the first line of treatment for CS
- A multimodal approach is needed to address CS

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## Action items

1. Screen CS in those with COPCs
2. Use validated questionnaires, CSI preop specially
3. Involve a multidisciplinary team in managing those with CS

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# CULTURAL AND LINGUISTIC COMPETENCY & IMPLICIT BIAS

The California Medical Association (CMA) outlines standards for Cultural Linguistic Competency and Implicit Bias in CME. The goal of the standards is to support the role of accredited CME in advancing diversity, health equity, and inclusion in healthcare. These standards are relevant to ACCME-accredited, CMA-accredited, and jointly accredited providers located in California. AAGL is ACCME-accredited and headquartered in California.

CMA developed the standards in response to California legislation (Business and Professions (B&P) Code Section 2190.1), which directs CMA to draft a set of standards for the inclusion of cultural and linguistic competency (CLC) and implicit bias (IB) in accredited CME.

The standards are intended to support CME providers in meeting the expectations of the legislation. CME provider organizations physically located in California and accredited by CMA CME or ACCME, as well as jointly accredited providers whose target audience includes physicians, are expected to meet these expectations which began on January 1, 2022. AAGL has been proactively adopting processes that meet and often exceed the required expectations of the legislation.

CMA CME offers a variety of resources and tools to help providers meet the standards and successfully incorporate CLC & IB into their CME activities, including FAQ, definitions, a planning worksheet, and best practices. These resources are available on the CLC and IB standards page on the CMA website.

**Important Definitions:**

**Cultural and Linguistic Competency (CLC)** – The ability and readiness of health care providers and organizations to humbly and respectfully demonstrate, effectively communicate, and tailor delivery of care to patients with diverse values, beliefs, identities and behaviors, in order to meet social, cultural and linguistic needs as they relate to patient health.

**Implicit Bias (IB)** – The attitudes, stereotypes and feelings, either positive or negative, that affect our understanding, actions and decisions without conscious knowledge or control. Implicit bias is a universal phenomenon. When negative, implicit bias often contributes to unequal treatment and disparities in diagnosis, treatment decisions, levels of care and health care outcomes of people based on race, ethnicity, gender identity, sexual orientation, age, disability and other characteristics.

**Diversity** – Having many different forms, types or ideas; showing variety. Demographic diversity can mean a group composed of people of different genders, races/ethnicities, cultures, religions, physical abilities, sexual orientations or preferences, ages, etc.

**Direct links to AB1195 (CLC), AB241 (IB), and the B&P Code 2190.1:**

Bill Text – AB-1195 Continuing education: cultural and linguistic competency.
Bill Text – AB-241 Implicit bias: continuing education: requirements.
Business and Professions (B&P) Code Section 2190.1

**CLC & IB Online Resources:**

Diversity-Wheel-as-used-at-Johns-Hopkins-University-12.png (850×839) (researchgate.net)
Implicit Bias, Microaggressions, and Stereotypes Resources | NEA
Act, Communicating, Implicit Bias (racialequitytools.org)
https://www.contemporaryobgyn.net/view/overcoming-racism-and-unconscious-bias-in-ob-gyn
https://pubmed.ncbi.nlm.nih.gov/34016820/
https://hr.ucdavis.edu/departments/learning/certificate/implicit-bias
https://pmc.ncbi.nlm.nih.gov/articles/PMC7011228/