Endometriosis:
The Critical Importance of Timely Diagnosis, Effective Management & Patient-Centered Care
A Multidisciplinary Approach
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www.endometriosis.ie
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A COEMIG-Designated Center of Excellence in Minimally Invasive Gynecologic Surgery
A Center of Expertise in Endometriosis

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"The most important thing when planning a patient's treatment for endometriosis is to LISTEN TO HER."

-Ken Sinervo, MD MSc FRCSC FACOG ACGE, Medical Director, Center for Endometriosis Care
Endometriosis Can Negatively Impact Every Aspect of Life

- Chronic or Intermittent Pain
- Increased Risk of Co-morbid Concerns
- Infertility Pregnancy Loss
- Organ Dysfunction
• **Endometrium-like** tissue found outside womb,\(^1\) resulting in sustained/inflammatory reaction; **NOT merely ‘normal endometrium’ or ‘misplaced endometrial lining in abnormal places’**

• **Substantial** morbidity, severe pain, organ dysfunction, impaired fertility, dyspareunia, etc. all common

• Current trends towards pain management explore novel options directed at oxidative stress, inflammation and nociceptive mechanisms of pain itself

• Efficacious treatment requires multidisciplinary approach\(^2\)

• Association with co-morbidities e.g. autoimmune disease, allergies, fatigue; rarely, certain cancers\(^2\)

• “Disease of theories”; definitive cause(s) remain under debate; hereditary, environmental, epigenetic and/or menstrual characteristics may exist

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• Significant diagnostic delays, high treatment failure with consequent recurrence/persistence

• Translational research lacking in priority; acute need for bench-to-bedside investigation

• Among leading causes of infertility, gyn hospitalization, hysterectomy\(^1,2,3\)

• Next generation: \(\geq 70\%\) of teens with pelvic pain later diagnosed\(^3\)

• Early intervention **CAN** reduce morbidity, infertility, progressive symptomatology\(^3\)

• Pelvic pain/infertility among chief clinical findings

• No known prevention

• Specific menstrual characteristics\(^1,^2\) may be associated
  • *Suggested decreased risk with late age @ menarche/shorter menstrual cycles with longer duration of flow*

• Near 10-fold increased risk in those with first-degree relatives who also have endometriosis\(^3\)

Endometriosis is a GLOBAL disease

• 176 million affected globally [WERF]
• 8.5 million estimated North America
• 155,000 estimated in Ireland

Commonly referred to as ‘disease of women’, but can impact menstruators/non-menstruators alike including rare males/trans-identified/gender non-conforming\(^1\); found in fetal studies\(^2\)

Significant loss of productivity: avg 11 hours per patient/per week; 38% more than those with symptoms who do not have disease\(^3\)

Economic Impact

• Intangible costs cannot be undervalued; 72% report having ≥ 8 endometriosis-related or coexisting symptoms interfering with daily life and work\(^1\)

• Direct costs considerable; largely driven by hospitalizations\(^2\)

• Total medical costs 63% higher than average\(^3\)

• Growing public health & societal crisis: fiscal tag of nearly $119 billion annually\(^4\); UK NHS costs alone=over £8 billion [Helen North, CEO Endometriosis UK]

• Global treatment market forecast: $1.31 billion by 2017\(^5\)

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Classic signs (including but not limited to):

- The Four Ds: *Dysmenorrhea, Dysuria, Dyspareunia, Dyschezia*

- Infertility/Pregnancy loss

- Cyclical/noncyclical pelvic pain

- Lower abdominal, leg, inguinal, back pain

- Nodules may be felt by bimanual rectovaginal exam

- Imaging may indicate pelvic mass/endometriomas

- Extrapelvic locations i.e. lungs, sciatic, diaphragm, beyond

- The Evil Triplets [Chung]: Endometriosis, Interstitial Cystitis & Pudendal Neuralgia
Dyspareunia Alone Represents Chief Critical Consequence:

- 21,746 women in 8 countries - 50% of respondents - indicated ‘dyspareunia’ as chief impact\(^1\)

- Less sexual/partnership satisfaction compared to patients with other gyn disorders (61% vs. 35%)\(^2\)

- Dyspareunia found less frequently in ovarian-involved cases (77%) compared to peritoneal (88%) and rectovaginal (100%)\(^3\)

- Excision improves dyspareunia & quality of sex life\(^4\)

- ‘Sexual health is a state of physical, emotional, mental and social wellbeing related to sexuality; it is not merely the absence of disease, dysfunction or infirmity...Sexual health is a global issue that is vital to overall wellbeing.’\(^5\)

3. Gruppo Italiano per lo Studio dE. Relationship between stage, site and morphological characteristics of pelvic endometriosis and pain. Hum Reprod 2001;16:2668-2671
5. Abdool et al., 2009
Common Sequela Include (but not limited to)

• Pain localization & severity/constant struggle for pain relief
• Loss of sense of self (i.e. femininity, feelings of isolation)
• Significant reduction in physical, emotional health
  – organ dysfunction; GI disruption (constipation, diarrhea, nausea, bloating, vomiting, fecal occult); urinary disorders; disrupted relationships; mental/emotional distress
• Negative impact on/disruption of school, career, religious practice adherence
• Disruption of casual life circumstances (social impairment)
• Infertility: “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse.”-International Committee for Monitoring Assisted Reproductive Technology & the World Health Organization

• Endometriosis along with PCOS/unexplained infertility is top 3 most common causes

• Woodruff et al.: ‘Fertility is greatest concern second only to mortality in both men and women’

• No single cause:
  • Endometriomas and adhesions interfere mechanically with ovulation and egg/embryo transport
  • Hostile intraperitoneal environment impairs ovulation, egg capture, tubal function
  • Anatomical impairment
  • Dyspareunia
  • Increased oxidative stress levels which lead to epigenetic changes

Endometriosis-Cancer-Malignant Transformation: What we (Sort of!) Know so far...

2-3x higher risk of ovarian endometrioid & clear cell carcinoma

Malignant transformation uncommon but occurs between 0.7–2.5% of cases; usually involves ovary

Prevalence of endometriosis in ovarian cancer:
-39.2% (198/505) for clear cell
-21.2% (147/694) for endometrioid malignancy
-3.3% (39/1173) for serous type
-3.0% (13/436) for mucinous type ovarian cancer

Patients with long-standing ovarian endometriosis reflect relative high risk of ovarian cancer

Significant predictors for malig transformation include cyst characteristics/age; >49 with multilocular cysts & solid components @ higher risk; CA125 NOT significant predictor of malig transformation
• NOT INFECTION OR SIMPLY KILLER CRAMPS!

• Can develop on any pelvic structure (many times, beyond)

• May occur more frequently on left side [Hsu et al.]

• Ovarian involvement most common; gastrointestinal tract, urinary tract, soft tissues, diaphragm follow (incredibly rare but possible: nasalacrimal, cardiac, brain)

• Rectovaginal septum, bladder, bowels, intestines, ovaries, fallopian tubes all routinely involved; endometriomas may represent DIE/DFE disease

• Pain Mechanisms: ‘Noci’-derivation from Latin for “hurt”: nociceptors-nerve cell endings that initiate sensation of pain [Ray et al.]; Sensitization-pt becomes more sensitive/gets more pain with less provocation [Woolf et al.]
  ✓ Peritoneal fluid in endo rich with inflammatory markers, pain-inducing prostaglandins, lipid peroxides, etc.
  ✓ Endometriotic tissue innervated with nociceptors, inducing constant pain cycle
  ✓ Hx of endometriosis=most likely to have sensitization [Stratton 2015]
**Pain Spectrum**

- Alterations in behavioral/central response, changes in brain structure, altered activity of hypothalamic-pituitary-adrenal axis & autonomic nervous system; psychological distress\(^1\)

- Decreased gray matter volume in regions involved in pain perception\(^2\)

- Lesions may develop own nerve supply, producing variety of differences in pain that can, in some, become independent of the disease\(^3\); proalgesic mediators (proinflammatory cytokines, chemokines, prostaglandins etc.) may be produced by lesions themselves, inducing pain loop\(^4\)

- Significant positive correlation: pain threshold and sleep quality\(^5\)

- Preclinical model demonstrated endo pain **alleviated by surgical excision**\(^6\)

Vesicular, red, white, blue, blue, brown, clear

Invisible disease: does it really exist?

Powder Burn Lesions: is it really endometriosis?

Vascular Abnormality

Adhesions/Scar tissue

Fibrosis/Irregular Surface Contours/Peritoneal Tension

Endometriomas
Invasive bowel lesion
© Robert B. Albee, Jr., MD
Endometrioma
R-ovary
© Robert B. Albee, Jr., MD
Examples of *Atypical* Peritoneum

Bowel serosa

© Robert B. Albee, Jr., MD
Examples of Atypical Peritoneum

Bladder peritoneum

© Robert B. Albee, Jr., MD
Appendiceal Endometriosis
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Large Bowel Endometriosis
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Small Bowel Endo

© Ken Sinervo, MD
After Bowel Resected
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Reconnected Bowel
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Sigmoid with Endometriosis
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To a Hammer, Everything looks like a Nail, but...

- Not all pathology/sources of pain will be endometriosis or endometriosis alone
- Prudent approach can assist in ruling out obvious other pathologies
Differential Diagnosis

- Adenomyosis
- Adhesions
- Appendicitis
- Diverticulitis
- Ectopic Pregnancy
- Genitourinary Infections
- Interstitial Cystitis
- Irritable Bowel Syndrome
- Leiomyoma
- Levator Ani Myalgia
- Mechanical Trauma
- Ovarian Cysts
- Ovarian Remnant Syndrome
- Ovarian Torsion
- Pelvic Congestion Syndrome
- Pelvic Inflammatory Disease
- Urinary Tract Infection
- Uterine Retroflexion
“Entities Must not be Multiplied Beyond Necessity” [Ponce, Ockham et al.]
• **No single theory sufficiently explains pathogenesis**

• Genetics, biomolecular aberrations in eutopic tissue, dysfunctional immune response, anatomical distortions, and pro-inflammatory peritoneal environment may all play roles\(^1, 2\)

• 3 distinct disease entities, possibly each with different pathogenesis: peritoneal, ovarian, deeply fibrotic\(^1\)

• 5 key processes of development: adhesion, invasion, recruiting, angiogenesis, proliferation\(^1\)

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• Redwine’s **Mulleriosis**: best describes origin; fetal development of endometriosis and allied pathologies explained – endopaedia.info

• Coelemic Metaplasia (spontaneous changes in the mesothelial cells)

• Sampson’s near-100 year old Retrograde Theory (remains popular, yet significantly flawed)

• Iron-induced oxidative stress (associated with inflammatory reaction)

• Stem cell origin (may differentiate into human endometrium)

• Elevated Cytokine Signature (inflammatory network) [Griffith 2014]

• Significant genetic contributions: genes, steroid hormone metabolism, immunological reactions, receptor formation, inflammation, proliferation, apoptosis, intercellular adhesion, cell invasion, abnormal expression of candidate genes leading to different epigenetic modifications [Baranov et al. 2015]

• **D.** All of above? **Combination of factors, later triggered in certain individuals likely**
• Possible dioxin/environmental pollutant link; data conflicts\(^1\)

• No particular demographic, personality trait, or ethnic predilection\(^2\)

• Inverse BMI relationship (lower BMI=higher risk)\(^3\)

• No definitive association with nutrition, exercise, personality traits or other lifestyle variables\(^4\) – you are truly NOT your disease

• Blue eyes, red hair: are women with endometriosis “more attractive”?\(^5\)

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Endometriosis is a **SURGICAL Diagnosis**; medical therapy neither diagnoses nor treats long-term.

Physical exam has poor sensitivity, specificity & predictive value; pelvic exam can reveal nodules, fibrosis, decreased/absent mobility.

Combination hx, physical, Copeptin/CA19-9/CA125/lab/imaging studies may r/o non-endometriosis concerns - **but do not r/o the disease**\(^1, \ 2\)

Absence of evidence is not evidence of absence!

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Do You See what I See?

- MRI superior to CT in detecting limits between muscles and abdominal SubCu tissues
- MRI accurately detects RVD/CDS obliteration in >90% of cases when gel inserted in vagina & rectum
- CT may reveal endometriomas as cystic masses
- Expert-guided TVUS more sensitive than routine; can identify lesions other than endometrioma and is of assistance in surgical planning/counseling [Fraser et al.]
- Sonographically visualized bowel lesions- have very characteristic appearance; "Comet Sign" - solid, focal, tubular with slightly irregular margins, thinner "tail“ at one end resembling a comet; extending TVUS to include evaluation of rectosigmoid helpful [Benacerraf et al.]

- Still: appearances may be nonspecific and imaging modalities should not be relied upon solely for diagnosis1-4

Laparoscopy - Primary Intervention for Definitive Diagnosis & Treatment

• Visualized findings upon surgical entry may represent “tip of the iceberg” disease presence

• Glands and stroma represent gold standard dx; fibrosis in combination with hemosiderin-laden macrophage may be sufficient for presumptive dx in some cases

• Emerging yet unproven technologies may be of little to no benefit and dramatically increase cost factors; **technology cannot replace skill**

• Accuracy of diagnosis often depends on **ability of surgeon to adequately isolate and identify disease** (typical/atypical)

• Work absence/performance loss/general negative impact on career reduced significantly by laparoscopic surgery [University Hospital of Bern, Wullschleger et al. 2015]
  - *net savings in indirect costs with present number of surgeries estimated near €10.7MM per annum [$11.3MM US]*

• Laparoscopic *Excision* (LAPEX) most minimally invasive, highly cost-effective, complete surgical option

• Reduced in-patient stays and post-operative morbidity lead to reduced costs and improved outcomes

• Repeated insufficient surgical/medical intervention due to incomplete non-excisional surgery *contributes greatly* to highly unnecessary increased financial burden on patient, hospital provider, practitioner and society
Hysterectomy/Bilateral Salpingo-oophorectomy

• Bilateral oophorectomy rarely indicated in patients < 40 years undergoing hysterectomy for endometriosis

• Goal: free ovaries, ureters and rectum from posterior vagina to the rectovaginal septum

• Deeply fibrotic nodular disease involving the cul-de-sac requires excision of fibrotic tissue from uterosacral ligaments, posterior cervix, posterior vagina, and rectum

• Remaining disease in anterior rectum and vaginal cuff frequently becomes densely adherent to, or invades, bladder and one or both ureters
Medical Suppressive Therapies

• GnRH, oral contraceptives, Danazol®, Visanne®, aromatase inhibitors, progestins etc. common mainstays

• **Superficial** surgical and medical treatments often fail

• No evidence that medical treatment improves fertility!

• Side effects may be intolerable/symptoms recur upon cessation of therapy

• Fertility eliminated during treatments
Adjunct Therapies: Alternative Medicine

- Naturopathy
- Exercise
- Osteopathy
- Aromatherapy
- Physical Therapy
- Herbal therapies
- Acupuncture
- Pelvic Massage therapy
- Diet & Nutrition
- Reduce exposure to toxins
- Pain Management
- Natural Progesterone
'Let food be thy medicine...’-Hippocrates

• Extremely complex to navigate; registered dietician can be of invaluable assistance. **IN GENERAL:**

• High antioxidant diet improves AO markers in blood level.¹ One study consisting of 150% of suggested daily intake of vitamin A, 660% of C, and 133% of E significantly reduced oxidative stress markers and enhanced AO markers in those with endometriosis²

• AVOID refined foods i.e. white breads, pastas, sugars; gluten free may help; personalized approach!

http://www.thenutritionista.ca ← The Nutritionista

Endometriosis: Healing through Nutrition by Dian Shepperson Mills & Michael Vernon
Deficient Awareness
Poor Information Systems
Lack of Authoritative Info
Late/Under-diagnosis
Normalization of Symptoms
Ineffective Treatments
Lack of Support/Validation
Withholding of Timely Referrals
Redundant/Limited Translational Research

We Deserve BETTER.
Delays in Diagnosis / Opposing Perceptions

• Doctor, Why Aren’t You Listening to Me?
  ➢ Inadequate pain perceptions by physicians vs. sufferers
  ➢ Differing perceptions between clinicians and patients re: symptomatology
  ➢ “It is necessary for physicians to [pay] sufficient attention to patient complaints...Ignoring complaints or normalizing them is a common reason causing delay in diagnosis.”-Riazi et al.

• Fertility Valuation vs. Quality of Life/Pain Eradication
  ➢ ...What we should be focusing on is not solely procreative potential or valuing an individual based on ability to conceive - but rather, on the impact which pain has on a person’s ability to enjoy their own choices, be they sexually, career or socially oriented.

• Patient Inability to Discriminate Between Normal & Abnormal Menses/Painful Cycles
  ➢ Inform early, inform correctly so individuals won’t ignore symptoms

• Patient Concealment
  ➢ Fear of stigma/taboo/culture of menstrual shaming can lead to diagnostic/treatment delay

Healthcare providers must engage patients in conversations which remain sensitive to cultural context, perceptions and attitudes, yet draw out possible symptoms and menstrual issues at first sign so they can be treated in a timely and effective manner.

Lack of Authoritative Information

Some teens, young women, caregivers, healthcare workers believe ‘killer cramps’ are normal; school absenteeism high yet endometriosis knowledge sorely deficient

Deficient health literacy at all levels is staggering

Some providers think endometriosis cannot affect a young/post-hysterectomy/post-menopausal patient

Society largely unaware of far-reaching impact and links to co-morbid conditions

Continued propagation of myths, misconceptions by media, practitioners, patients; generation to generation
Quality Research: Unmet Needs

➢ ‘Research focus must be shifted to better clarifying pathogenesis and pain mechanisms as well as link to certain morbidities’ [Hummelshoj]

➢ Lack of translational, redundant efforts lead to little progress (same people publishing variation on same theme; literature often missing substantial contribution by experts in non-academic setting – for majority of high volume surgeons in private practice, journal submissions are subsequent pursuits with clinical activity demanding most time and energy)

➢ Until we “recognize the lack of large scale international clinical trials, lack of funding for research and, not least, the potential overlap of effort from country to country when centers work in isolation and can’t share data”¹, we will never find preventive strategies, non-invasive diagnostic methods nor ultimately, cure.-Professor Robert Schenken; World Endometriosis Research Foundation. Press Release 12/11/2006
“TEAM:” A multidisciplinary group composed of members from different healthcare professions with specialized skills and expertise; working together to provide care for best functional outcomes.

Need not be housed under same organizational umbrella
General Care Provider/Nurse Practitioner/Radiology-Imaging/Gyn/MIGS & Subspecialty Surgeons (gastroenterology, urology, etc.)/Reproductive Endocrinology/Psychology/Pain Management/Allied health (nutritionists, physiotherapists, health educators, patient advocates, social workers, alternative practitioners, healing arts, etc. etc.)/Support groups
Plan+Prepare = Proper Intervention
Multidisciplinary/synergistic approach:

• Physical exam/RV-bimanual exam
• Imaging pearls (presurgical assessments may be key particularly in DFE/rectovaginal cases)
• Urology (cystoscopy? resection? stents?)
• GI (sigmoidoscopy? colonoscopy? full thickness resection?)
• Preop Consults (GynOnc? Gen surg? Anesthesia? Pulmonary?)
• Informed Consent/Patient-Centric Interviewing
The Surgeon: Tertiary Referral Centers for Laparoscopic Excision

• Excisional biopsy and removal most effective treatment for superficial and deeply invasive disease; also allows for histological confirmation

• Confers high rates of relief and symptom suppression of 57-66% at re-evaluation\(^1\)

• Laparoscopic Excision restores normal anatomic relationships and treats pelvic pain, infertility, or both by sharply dissecting deep fibrotic nodules which may be causing partial or complete cul-de-sac obliteration

• 24-month follow-up of 240 patients\(^2\) comparing excision alone, laser ablation alone, or laser ablation+medical therapy at 1 year out:
  - 96% of excision patients pain-free
  - 69% of ablation pain-free – only 23% at 2 years out

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Reproductive Endocrinology

- Surgical/medical/alternative intervention; can also treat both male and female factor

- Fertility preservation is goal; team may consist of RE, embryologists, clinical nurses, technicians, lab staff

- Has experience in multiple causes of infertility

- Key team member particularly in patients for whom excision/other surgical intervention has “failed” and infertility persists
Psychological Support\textsuperscript{1, 2, 3, 4, 5}

NOT because it’s in her head!

Endometriosis is associated with significant impairments in pain, psychological functioning and social functioning.\textsuperscript{1}

Significant correlations exist between the severity of mental shifts and the immuno-patho-genetic/psycho-neuro-immune components of endometriosis.\textsuperscript{2}

Dyspareunia, a common complaint in patients with endometriosis, can – on its own – cause severe impairment of sexual function, relationship and psychological wellbeing.\textsuperscript{3}


• Endometriosis causes considerable negative impact on quality of life, especially in the domains of pain and psychosocial functioning.¹

• “This disease can cause physical and psychological damage; therefore, it is really important to develop a multidisciplinary approach in the aim to offer the appropriate treatment.”-Dell'oro, Collinet, Robin, Rubod C.²

Pain Management

“Chronic pain is defined as persistent pain, which can be either continuous or recurrent and of sufficient duration and intensity to adversely affect a patient's well-being, level of function, and quality of life.”-Agency for Healthcare Research and Quality, US Dept of Health & Human Services

Pain medications may work best in those with only mild symptoms; ranging from OTC pain relievers to prescription pain relievers-Eunice Kennedy Shriver National Institute of Child Health and Human Development

Pain management = pharmacological measures i.e. analgesics, tricyclic antidepressants; interventional procedures, physical therapy, physical exercise; application of ice and/or heat, and psychological measures, e.g. biofeedback and cognitive behavioral therapy.-Institute for Clinical Systems Improvement (ICSI). Assessment and management of chronic pain. Bloomington (MN): Institute for Clinical Systems Improvement (ICSI); 2011 Nov. 112 p.
The Art of ‘Hands on’ Healing: Physical Therapy

“After physical therapy interventions, patients saw a decrease in the impact of their symptoms on their lives and a decrease in the dissatisfaction of their lives. Therefore physical therapy is an essential component when treating persistent endometriosis pain.”
– Dr. Sallie Sarrel, PT, ATC, DPT

Fertility-enhancing massage may also be done in a number of settings under various protocols e.g. Clear Passages Therapy

Peer Support & Education

• Patient Advocates – ‘guardians of the patient’s rights’

• Group settings can provide mutual aid and self-help for people facing chronic disease [Cline et al.]

• Benefits include enhanced quality of life, improved decision making, timely resources/referrals and sense of empowerment [Braithwaite, Spiegel et al.]

• Online format offers 24/7/365 access; asynchronicity allows individuals to develop responses at own speed; geographic/mobility/transportation barriers absent [Dorman, Madra]

• Drawbacks include dangerous or mistaken medical information [Winzelberg]; deception [Rheingold, Madara]; commercial interests recommending expensive/ineffectual treatments [Winzelberg]

• In all, peer-to-peer support can serve as useful utility in self-care and management
Application of Modern Concepts: Outcome at 24 Years

Center for Endometriosis Care:
• More than 8,850 total procedures since 1991
• Recognizes subtle disease in all its manifestations
• Preserving organs through meticulous EXCISION
• Performs pathological examination on all excised tissue; and
• Treats patients with respect and compassion as partners in their health care

Outcomes to date:
• 85% of patients experience long-term relief, even in higher stages
• Improved fertility even in higher stages (50% stage 4)
• Recurrence of endometriosis ranges between 7%-8%
• Overall likelihood of repeat surgery is less than 12% with unrelated outcomes (fibroids, adenomyosis, adhesions, etc.)
• Stark contrast to general recurrence rate within first year of superficial surgery - 44-60%
"A candle loses nothing by lighting another candle.” - Fr. James Keller

Mayo Clinic on Benefits of Social Support Network:

A network of supportive relationships contributes to psychological well-being...including-

**Sense of belonging:** spending time with others helps to ward off loneliness/despair/stress

**Increased sense of self-worth:** having supportive people around reinforces the idea that you’re worthy (which of course you are!)

**Feeling of security:** social networks give access to information, advice, guidance and other types of assistance

**Comfort:** knowing you’re not alone and have people to turn to in a time of need can be critical to help through tough times
“When patients and families take a more active and shared role—partnering in their health, healthcare, and the healthcare system as a whole—everyone benefits.”-Moore Foundation & American Institutes for Research
What Providers can do:

--Moore Foundation & American Institutes for Research

• Educate patients and families about their health and healthcare and support and encourage them to take an active role

• Implement/direct towards patient advocate/navigator programs

• Support patients in managing their own health

• Prepare patients & families to partner with researchers

• Prepare patient and family representatives to partner with other stakeholders in local, state, and national policy and programmatic decisions

• “Empathy has a beneficial impact on others in medicine...conceptual framework may also help explain why sometimes the best medicine is simply having someone to care for you...”-Decety, Fotopoulou 2014
What Patients & Caregivers can do:

---Moore Foundation & American Institutes for Research

• Give feedback on your experiences to others, including caregivers/health providers

• Seek out quality/accurate information to help you understand your condition

• Prepare for your next appointment by writing down important health information including medications, current symptoms, questions; keep track of and organize your medical information

• Contact your clinic or hospital and volunteer to be a family advisor

• Many epidemiological studies have further linked measures of social support to physical health outcomes – seek out a support system/group

• Interdisciplinary perspectives on social support and health indicate robust relationship between social and emotional support from others as protective/beneficial for health [Reblin et al.]
Putting an end to the Secrecy, Silence, Shame & Pain

Revitalizing menstrual communication & key conversations we need to be having with our patients – and sisters, daughters, selves
• It is critical the public, including but not limited to, legislators, hospital administrators, gynecologists and subspecialists becomes involved in the care of patients.

• Empowering patients reduces the stressors of the disease [Seear]

• *We MUST work together to support efforts towards timely knowledge of pathophysiology, early recognition and correct diagnosis, understanding of pain mechanisms, increased recommendations for management and significant improvement of surgical quality, accessibility and affordability*. 
• Support multi-disciplinary approach for improved outcome and reduced costs

• Education must start in the school setting and across multidisciplinary healthcare provider centers i.e. clinics, Planned Parenthood, primary care physicians, community health centers, gastroenterologists, urologists, etc. through dissemination of updated, current and authoritative data

• STOP FAILING THE INDIVIDUAL WITH ENDOMETRIOSIS. Increased “awareness of endometriosis as a disease with substantial morbidity is vitally important.”

En Précis...

- Endometriosis severely diminishes physical, sexual, reproductive and emotional health

- Relationships, careers, academics, sexuality, fertility and overall quality of life negatively impacted

- Longitudinal benefits will be achieved if we evolve towards a paradigm shift that defines most favorable treatment policies by integrating advances in technology
"We can let the circumstances of our lives harden us so that we become increasingly resentful and afraid, or we can let them soften us, and make us kinder. You always have the choice."

-Dalai Lama-
Center for Endometriosis Care

*a COEMIG-designated Center of Excellence*

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