

Does DES Cause Spine or Lower Back Problems? Not Enough Data to Say.

Back pain is one of the most common forms of chronic pain and traces back to the changes in our lifestyle brought on by the Industrial Revolution. (Automation, assembly lines and more sedentary jobs affected how our musculoskeletal physiology changes over our lifetimes.)

But some in the DES Community have experienced more severe forms of back pain or other spinal problems, such as scoliosis or lumbar issues. We dug into the research to see if we could find any evidence that potentially links DES exposure to spine- or lower back-related conditions.

One reason we thought a link might exist is the known increased risk of osteoporosis among DES Daughters. There’s also good evidence from animal studies showing that exposure to estrogens during early development can affect the musculoskeletal system.

However, as is so often the case when we’ve sought answers from the research, there was not nearly enough evidence for us to find satisfying answers. We’ll review what we were able to find, however.

An experimental study published in *Arthritis Research and Therapy* in 2012 investigated the effects of DES specifically on several bone regions: the lower back (lumbar), the thigh (femoral), the cartilage at the end of each bone in a joint (articular cartilage), and the disks between each vertebra in the spine (interver-

tebral discs). (DOI: 10.1186/ar3696)

The researchers gave pregnant mice either peanut oil (for comparison) or 0.1, 1 or 10 micrograms per kg of DES each day during days 11 to 14 of gestation. After birth, one group of mice were conditioned to swimming while the other was kept sedentary.

Then the researchers measured their bone mineral density, bone mineral content, overall bone area, and the bone area at the end of the femur bones and the spine vertebrae. Their findings varied based on the sex of the mouse and the dose they

were exposed to.

Bone content in the lower back was higher in females who received the highest and lowest doses of DES. Thigh bone content was higher only in females with a higher DES dose. However, males who received the highest DES dose had lower bone content in the lower back and thigh.

“Results suggest that environmental estrogen contaminants can have a detrimental effect on the developmental lumbar bone growth and mineralization in mice,” the re-

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New and Improved Doctor Search Directory Now Available

Check out the new, improved and much easier-to-use doctor directory on the DES Action website at doctors.desaction.org. If you’re already logged in to the DES Action website as a member and you go to doctors.desaction.org, you’ll be able to search by city, organized by distance, or by specialty.

Specifically, the new doctor directory allows visitors to limit their search by varying distances, such as a radius of one, five, 10, 50 or more miles from a particular zip code or city, instead of just searching for the health care providers within a particular zip code

or city.

If you arrive at the doctor search page while not yet logged in as a member, you’ll have to log in there before you can search since this is a benefit exclusive to DES Action members.

We are continually updating our doctor list and adding health care providers that you recommend, so if you have any suggestions, please email them to our DES Action USA Community Manager at cheyenne@desaction.org. Thank you to all the DES members whose support helped us update this resource.



News From International Sister DES Organizations

Our sister DES organizations in two European countries are working hard to increase public awareness and shape public policy related to DES-exposed individuals.

France's Réseau DES France recently released its revamped website with user-friendly information on the consequences of DES exposure, scientific findings, information about DES as an endocrine-disrupting chemical, and summaries of legal issues, including imposition of liability in only three countries: France, the Netherlands and the USA. The opening video clip "DES Women" on www.des-france.org is not to be missed!


France's second DES organization, D.E.S. Is It, produced an engaging video clip that explains

what DES is: "an inefficient and dangerous drug prescribed to pregnant women, a synthetic estrogen easy to produce that allowed pharmaceutical companies to make a lot of money... an endocrine disruptor which affected gene expression... We inform people that they may have been exposed without even knowing it, and invite them to join us." Go here to watch: <https://youtu.be/3oNTNkdgdKQ>

Finally, the organization DES In Belgium (DIB at www.desbelgium.be) has an ambitious agenda for the next two years: they are working toward "the recognition, medical follow-up and preventive cancer screening of everyone who is a victim of DES in Belgium." At two roundtable discussions on February 12, 2021, and March 18, 2022, DIB

planned a conference for "DES stakeholders, experts, government and possibly other parties involved" to "come together to map DES in Belgium, but above all to recognize the victims."

Speakers will include historian Antje Van Kerckhove, who obtained her master's thesis in 2021 on the dissemination of knowledge of the DES hormone in Belgium since 1971, and filmmaker Guido Verelst, who is making a documentary about his great-niece, DES granddaughter Anne Verelst.

These efforts of three of our sister DES organizations are informative and inspirational, and great examples for all of us in the international community of DES-exposed individuals. 

Renew Your Membership

It's easier than ever to renew your membership. Just log into the site using the email you registered with and your password. If you don't remember your password, you can reset it.

If you no longer use the email you signed up with, send your new address to Cheyenne Chapman at cheyenne@desaction.org. She will set a temporary password for you.

Thank you for supporting DES Action USA with your membership.



MISSION STATEMENT

The mission of DES Action USA is to identify, educate, empower and advocate for DES-exposed individuals.

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Q&A with Linda Marks, DES Daughter

Linda Marks has spent most of her adult life in DES advocacy. She shares her story here.

Tell us about first finding out about your DES exposure.

I think it was about 1974—the spring of my freshman year—when my mom sat me down at the kitchen table and told me she found out that something she had taken when she was pregnant with me may have affected me.

She was serious, and very concerned. I think she had read an article in the L.A. Times about DES, then called the OB-GYN who delivered me, and who she was still seeing, to ask whether she took DES. She then took me to see him – my first OB-GYN visit, which was pretty terrifying.

Have you had conversations with your mom over the years about DES and what we've learned about it?

Absolutely. After the first visit with the OB who delivered me, he recommended that I see someone who was starting to see DES Daughters, Dr. Duane Townsend. Mom always went with me to my appointments, which were at least twice a year, and sometimes more frequently.

The year after I graduated from law school, in spring 1981, either my mom or I saw a notice for a meeting of a local DES Action group. We went to the meeting, and to my surprise, we were the only mother-daughter team there—something that sticks with me to this day.

There were DES Mothers who couldn't bring themselves to speak to their daughters (at that time, there wasn't too much information on DES Sons), and DES Daughters who were mad at their mothers for taking DES.

I was never upset with my mother. In the 1950s, you accepted everything your doctor told you, and if he said to take this pill and



Linda Marks with her mother

it'll help your pregnancy, you took the pill. If anything, she took DES because she very much wanted to have a child, and at 34 years old was on the “older” side of childbearing.

After that first meeting, I became actively involved with the L.A. chapter of DES Action, which was being run by two smart, wonderful women, Laura and Wendy. We ran public meetings at local hospitals, did PSAs and provided information about the effects of DES and suggested practices for gyn examinations, such as colposcopies and 4-wall PAPs. We were later joined in our efforts by Paul, a DES Son, as the effects on DES Sons were becoming known.

While I was co-running DES Action, our group was contacted by Dr. Art Ulene, then a medical reporter at a local L.A. TV station, who was looking for a mother-daughter duo to go on his show and talk about DES.

My mom and I did the show. I was, and still am, so proud of my mother for agreeing to go on camera and speak about her experience. It wasn't easy for either of us.

She also came with us when DES Action staffed a booth at what was called “the last ERA Rally,” held at a park in Los Angeles, and handed out pamphlets. So it's never been something we avoided discussing.

I continued my involvement with the L.A. chapter of DES Action until I moved away from Los Angeles in fall 1982, and I have remained a member ever since.

In what ways has being exposed to DES impacted your life over time?

In my third year of law school, I took a consumer law class and did my final paper on DES, including how it got on the market but mainly focused on DES litigation that was happening. I suppose it was a precursor to working as a consumer fraud prosecutor.

What do you want others to know about DES and its impact on people in the DES-affected community, or even more broadly?

I'd like DES Daughters and Sons to pass on information of their DES exposure to their children so that they have a complete family medical history. And I'd like medical, nursing and medical tech schools to be aware of DES and its effects. I am still astounded that medical history forms make no mention of DES exposure or that radiology techs conducting mammograms have never heard of DES.

Tell us about your involvement with DES Action over the years.

While in the Los Angeles group, we were visited by a reporter writing a book on DES. Some of us were interviewed and ended up in D.E.S.: *The Bitter Pill* written by Robert Meyers.

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Filmmakers Discuss Psych Drugs in “Medicating Normal” Panel

As the biggest pharmaceutical disaster in U.S. history, DES is the prime example of a drug that offered no benefit to the millions of women who took it during pregnancy, but it caused immense harm.

Today, most drugs approved by the U.S. Food and Drug Administration do offer benefits for a condition, but all drugs have side effects—and many people may be prescribed drugs whose side effects are worse than any possible benefit they might experience. Others have been prescribed drugs they never needed in the first place.

As part of our mission to educate others about the potential harms of approved medications, DES Action USA and our sister organization, MedShadow, partnered with producers of the film *Medicating Normal* to host a panel discussion on the harms that can result from certain

and Wendy Ratcliffe note that an estimated one in five Americans is taking an antidepressant or anti-anxiety drug, but about a third of these individuals, the filmmakers say, are harmed by these medications.

“*Medicating Normal* focuses on the predicament of this group—individuals facing trauma and stress who are drugged needlessly and made sicker as a result,” the filmmakers write. “Interviews with experts in the film reveal that significant numbers of these people will get better over time without medication.”

They add, “These medications often provide effective short-term relief for emotional distress and other problems, but pharmaceutical companies have hidden common side effects and long-term harm from both patients and doctors.”

After hosting a viewing of the film for the general public, DES

treatment for medical conditions. They both are members of MedShadow’s Medical Advisory Board.

Several themes emerged from the discussion, including the question of whether these psychiatric medications qualify as “addicting” when people develop a dependence on them.

Green pointed out not only that terms like “dependence” and “addiction” are complex—especially considering physiological versus psychological dependence—but also that they carry stigma that complicates how we think about them and the medications that lead to dependence.

The fact that the drug is intended to treat mental health further complicates the problem because the withdrawal symptoms are both physical and psychological.

“Do I think I need this medication [for mental wellness]? Or does my body now have a terrible time stopping this medication because I’m going through these [physical] withdrawal symptoms?” Green said. “I think the movement has been to stop using the word ‘addiction’ and to be very cautious about how we describe dependence.”

Green’s daughter, Rebecca, was prescribed drugs that worsened her life instead of improving it, such as causing hallucinations that were “right out of a horror movie,” Green said.

Yet when he brought up the possibility that the medications were causing the hallucinations—rather than them being part of a medical condition the drugs were intended to treat—“I was talking to a brick wall,” he said. Rebecca’s parents helped her stop taking the drugs altogether, and she has been doing better since.

Rebecca still has anxiety, but she’s learned to identify her trig-

“It’s really the people going through it who are helping each other. They are learning from each other. They’re giving each other support and encouragement on the websites.

— Lynn Cunningham, *Medicating Normal* filmmaker

psychiatric medications.

Medicating Normal is a documentary that shares the story of several individuals who were initially prescribed a medication for depression, anxiety or a similar mental health concern.

But the medication didn’t help them. Instead, it sent each person down a destructive path that irrevocably changed their lives in ways that most people prescribed these drugs aren’t aware of.

The film’s executive producers and directors Lynn Cunningham

Action director Suzanne Robotti moderated a discussion with Cunningham as well as Todd Green and Joe and Terry Graedon.

Green’s daughter, Rebecca, was one of the individuals featured in the film who suffered the effects of psychiatric medications.

Joe Graedon, a pharmacologist, and Terry Graedon, a medical anthropologist, are founders of the People’s Pharmacy, which aims to empower people with the information they need to make informed decisions about their health and

gers and use methods learned from mindfulness and cognitive behavioral therapy to manage them.

“I actually look up to her now,” Green said. “My daughter is someone who struggles with a lot of things that a lot of us struggle with, but she has found ways to cope with that and to be mindful of what’s going on in the environment. At the time, medications sort of dulled her to all that.”

Green and his wife had trusted doctors in that taking a pill would improve their daughter’s condition. They hadn’t considered that the medication could interfere with her developing necessary coping skills to deal with life’s challenges.

Little to no guidance exists on how to stop or wean off psychiatric medications like those in the film, so for many, “it’s a do-it-yourself project,” Green said.

Robotti read questions from viewers watching the discussion, including one person who had stopped taking psychiatric medications five years earlier but never returned to feeling like themselves. “What do I do now?” they asked.

The problem, Terry Graedon said, is that we don’t have enough research to adequately answer that question.

“We don’t have the studies to say, here is how you get off these medi-

cations, here is the natural history after you’re finished with the withdrawal, here is how you get back to your old self, the parts of you that you really loved,” Terry said. “We don’t have that information.”

One of the challenges, Joe explained, is that people may start a medication that genuinely offers them a benefit, but once they no longer need it, the withdrawal symptoms are so severe and powerful that they’re unable to stop taking it—even if they don’t actually need it anymore.

Those withdrawal symptoms blur the lines in distinguishing between symptoms that mean the person actually needs the drug and the experience of withdrawal that is supposed to eventually go away—if they can ever quit the drug.

The manufacturer for one such drug told the Graedons that the medication should be fully out of a person’s system within a few days. But as the Graedons dug into the research, they learned that changes in a person’s brain chemistry meant that the withdrawal effects could last for months.

“Some people are super sensitive to the changes that happen, and we don’t completely understand why they don’t recover,” Joe said. “We just don’t have a good formula to get people back to ‘normal,’ so what such


a person needs is a health professional who will listen, who will work with this person and try to come up with a program that will help them recover without substituting more drugs.”

Cunningham said that during the research phase of producing the film, she and Ratcliffe spoke with more than 100 people across the country who shared remarkably similar experiences.

“The pattern is the same,” Cunningham said. “The feeling that they were not believed by their doctor, they were not taken seriously. They were often told, ‘The drug is out of your system,’ and it was said over and over.”

They’ve continued to hear these stories during screenings, and support groups exist, but it’s been very demoralizing not to have the research to offer concrete suggestions to these individuals, Cunningham said.

“It’s really the people going through it who are helping each other,” she said. “They are learning from each other. They’re giving each other support and encouragement on the websites, and I would say go to the websites, listen, learn, ask questions, because people really want to help each other.”

You can rent the documentary on Amazon Prime and watch this panel discussion on the DES Action website or Facebook page. -TH 

Common Diabetes Drug Linked to Birth Defects in Boys

Boys born to fathers who were taking a common diabetes medication shortly before conceiving them were more likely to have birth defects than children whose fathers took insulin but not metformin for diabetes, according to a recent study.

Sperm takes approximately three months to fully develop, so the study authors defined an infant as “exposed” if the father was

prescribed a type 2 diabetes medication in the three months before conceiving the child. The medications they studied were insulin, metformin, and sulfonylureas (an older class of diabetes drugs).

The researchers analyzed data from 1.1 million children born in Denmark from 1997-2016 to mothers with no history of diabetes or high blood pressure. The study

excluded multiples, such as twins or triplets. The study was funded by the National Institutes of Health and the CDC and published in the *Annals of Internal Medicine* (DOI: 10.7326/M21-4389).

“Given the prevalence of metformin use as first-line therapy for type 2 diabetes, corroboration of these findings is urgently needed,” wrote

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Common Diabetes Drug Linked to Birth Defects in Boys

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Germaine M. Buck Louis, PhD, a reproductive and perinatal epidemiologist at George Mason University, in a commentary about the study (DOI: 10.7326/M22-0770).

“Meanwhile, clinical guidance is needed to help couples planning pregnancy weigh the risks and benefits of paternal metformin use relative to other medications,” Buck Louis wrote. “Important in this guidance will be communicating that the adverse relationship was specific to metformin during the period of [sperm formation].”

Study Findings

A total of 7,029 fathers had taken any diabetes drug at all during the time they would have conceived the children in the study. Among the 5,298 children conceived with sperm exposed to insulin, 3.3% had at least one major birth defect, compared to 5.2% of the 1,451 infants conceived with sperm exposed to metformin and 5.1% of the 647 infants conceived with sperm exposed to sulfonylureas.

After making adjustments for the children’s birth year and their mother’s and father’s age, income and education, those conceived with sperm exposed to metformin had a statistically significant 40% higher risk of birth defects.

A 40% increase means for every 10 babies conceived with sperm exposed to insulin who had a birth defect, there were 14 babies conceived with sperm exposed to metformin who had a birth defect. For example, out of 1,000 babies conceived with sperm exposed to insulin, about 33 would have a birth defect while 46 of 1,000 babies conceived with sperm exposed to metformin would.

Only genital birth defects appeared more frequently in the metformin exposure group, and only in boys. A total of 0.9% of metformin-exposed children had genital birth

defects compared to 0.24% of all children in the study not exposed to metformin. The risk of genital birth defects in metformin-exposed children was about three times higher than in those not exposed to metformin.

Other Drug Risks?

There was also a 34% increased risk of birth defects among babies conceived with sperm exposed to sulfonylureas, but this finding wasn’t statistically significant, and there wasn’t any increased risk of genital birth defects.

It’s not clear if the lack of statistical significance is because there’s no association or because too few fathers were taking sulfonylureas to get a reliable calculation, especially since 44% of fathers taking sulfonylureas were also taking metformin. There weren’t enough fathers taking other medications to find out if there was an increased risk of birth defects for children exposed to other diabetes drugs.

No Siblings’ Risk

The researchers also looked at outcomes for babies of 1,751 fathers who filled metformin prescriptions in the year before conception, 1,861 fathers who took metformin more than a year before conception, 2,484 fathers who took metformin the year after conception, and 28,112 fathers who took metformin more than one year after conception.

In all cases, the rate of birth defects was not statistically different than the rate in infants conceived with sperm exposed to insulin and not metformin. Those conceived with sperm exposed to metformin during the year of conception actually had an even higher risk (75% greater—not quite double the risk) than infants whose fathers took metformin at least a year before or after conception.

The unexposed siblings of exposed children also had similar birth defects rates as other unexposed children (3.2%). Their metformin-exposed brothers and sisters had a 1.5 times

higher risk than they did. That finding was not statistically significant, but it could have missed significance because there were too few siblings for a reliable calculation.

What It Means

This study does not conclusively show that men taking metformin in the three months before conceiving will increase their child’s risk of a birth defect. It’s possible that fathers taking metformin have some other factor in common contributing to the risk.

For example, those prescribed metformin may have another physiological issue related to glucose management or obesity that’s involved. Still, the association between metformin and birth defects is high enough that the link could be metformin. The researchers aren’t sure why metformin might have that effect.

Also, the study was based on who filled prescriptions, which doesn’t reveal who actually took the medication as directed or whether their physician changed the drug later on.

Regardless, the findings highlight the need for more research into the effects of metformin in conceiving children, especially when it’s such a commonly prescribed drug for such a common condition.

About one in 10 Americans—more than 37 million people—have diabetes, and 90-95% of these cases are type 2 diabetes. In 2019, metformin was the fourth most commonly prescribed medication in the U.S., with more than 85 million prescriptions written for over 17 million patients.

These findings should lead to targeted basic research to learn whether metformin is causing birth defects and, if so, how, wrote Buck Louis, the epidemiologist who penned a commentary on the study.

She also noted the value in continuing to promote healthy lifestyle behaviors that can improve type 2 diabetes, such as reduced sugar intake, a healthy diet, and regular physical activity. -TH



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searchers concluded.

The problem is that we don't have great evidence for understanding what bone content levels mean in humans. Generally, more bone content means higher bone mineral density.

Low bone mineral density is linked to a higher risk of fracture, and high bone mass has been linked to higher fat mass in women.

A high bone mineral density has been linked to degenerative spinal disease and a few rare diseases, but it's not clear if this increases the risk of the disease or if the disease has an effect on increasing bone mineral density.

That study tells us that there's a theoretical basis for saying that some dosage of DES could have an effect on the bone development and overall content in the lower back and thigh, depending on whether the exposed person is male or female.

The problem, however, is that we don't know how that translates to humans and what it would actually mean in humans. Does that mean that DES Sons might have a higher risk of lower back problems because of lower bone content? We can't say that.

Does it mean that DES Daugh-

ters who have a moderate amount of DES exposure — not a lot but not a very small amount — would have a higher risk than other DES Daughters of having lower back issues or even scoliosis? Again, this study doesn't give us any evidence to say that.

To know whether there's a link between DES exposure and lower back problems, scoliosis and other spinal issues, we would need to have more, and more definitive, animal evidence as well as epidemiological evidence from population studies in DES Daughters and Sons.

There is a smattering of other animal studies, but not enough to draw reliable conclusions. For example, a 2016 study found that olive oil offsets estrogenic effects on the lumbar bone in mice. (DOI: 10.3892/etm.2016.3138) But the study was focused on olive oil's effects, not the estrogen's.

Further, another study suggests that estrogen's effects on bone are positive. That study, published in 2010, compared the effects of corn oil and another compound on the spine and notes that DES caused improvements in bone mineral density. (DOI: 10.3945/jn.109.116343) That fits with what we know about menopause, when it's the reduced production of estrogen in the body that contributes to an increased risk

of osteoporosis.

Another study, from 2008, similarly found that DES led to stronger bone mineral density in the lower back vertebrae of female mice, which made those vertebrae "stronger" and "more resistant to fracture." (DOI: 10.1080/15287390801988947)

Males exposed to DES in that study, however, had poorer bone mineral density in the spine, suggesting that DES may strengthen the lower back in females but weaken it in males. (The study doesn't prove that's happening, but that's what the evidence seems to point to.)

None of that evidence is enough to draw firm conclusions about the risk of scoliosis, spine or lower back issues in people exposed to DES. Further, none of the population studies in DES Daughters or Sons has identified any increased reports of back- or spine-related problems.

Ultimately, that means we weren't able to find any evidence that DES exposure is related to back or spine issues. We can't necessarily rule it out, but if there is an effect, it's either too small or too rare to show up in research, or it affects males (a less tracked group) but not females and therefore hasn't been found. Right now, there's no evidence that DES contributes to spine or back problems. -TH



Q&A with Linda Marks, DES Daughter

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It was published in 1983, and by then I had moved to Washington, D.C. I just looked at the subtitle, "How Medical Indifference Turned a 'Miracle' Drug Into a National Nightmare," and thought about the parallels with opioids — not related to the physical effects, but how millions of people can be adversely affected by a supposedly safe drug prescribed by physicians.

I was pleased to attend the first big DES Action meeting in 1981

and met Pat Cody, the founding mother of the group. Without Pat's guidance, DES Action wouldn't still be helping those affected by DES.

And I was honored to serve on DES Action's board before it transitioned to being part of MedShadow. Along the way, I've met enthusiastic, dedicated, smart, talented women who have become friends, and I can thank DES Action for that. Being a part of DES Action for over 40 years has been a valued and cherished part of my life, and I will continue to support it and encourage others to do so.



New Endometriosis Guidelines Emphasize Hormone Therapy

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gonadotropin-releasing hormone (GnRH) agonists are prescribed. These medications block the pituitary gland from making two types of hormones, follicle-stimulating hormone (FSH) and luteinizing hormone (LH).

In teens with symptoms of endometriosis, first-line treatment is hormonal birth control or progestins. In post-menopausal patients, however, the guidelines advise against estrogen-only treatments. -TH



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New Endometriosis Guidelines Emphasize Hormone Therapy

New guidelines from Europe on the treatment of endometriosis emphasize using more hormone therapy and less laparoscopy. The guidance, released in February, came from the European Society of Human Reproduction and Embryology.

It's not clear, however, the extent to which these guidelines will affect care in the U.S. Guidelines are not binding—that is, doctors aren't required to follow them—but they do set the standard of care. Usually, guidelines in Europe and the U.S. are very similar.

The last update to endometriosis guidelines in the U.S. from the American College of Obstetricians and Gynecologists, however, was in 2010. Those guidelines note that,

aside from NSAIDs, such as ibuprofen, the main medications used to treat endometriosis are hormonal medications, including birth control pills, progestin-only medications and gonadotropin-releasing hormone (GnRH) agonists, according to ACOG.

"Hormonal medications help slow the growth of the endometrial tissue and may keep new adhesions from forming," ACOG notes on their website. "These drugs typically do not get rid of endometriosis tissue that is already there."

The newly released European guidelines are the first update since 2014 and are based on research published up through December 2020.

The biggest change is that lapa-

roscopy is no longer recommended for diagnosis. Instead, it should only be used in patients whose symptoms don't improve after receiving medications but whose imaging results don't show evidence of endometriosis.

The reason for this is that a laparoscopy is still invasive surgery, and doctors can treat a case of highly suspected endometriosis based on the patient's clinical symptoms and/or evidence of a cyst from a pelvic exam or imaging from ultrasound or MRI. If a patient improves with medication, then they have endometriosis.

The first medications usually prescribed are NSAIDs for pain. If those aren't adequate, either hormonal birth control or drugs called

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