

## HER BODY

## Pat Wingert and Barbara Kantrowitz

## A Hidden Pain

Why a famous beauty like 'Top Chef' host Padma Lakshmi is talking about a very unglamorous disease like endometriosis.

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For Padma Lakshmi, a former model and host of Bravo's "Top Chef," the problem began when she was a teenager. "I'd always had very bad menstrual cramps, and they got progressively worse over the years," Lakshmi says. She tried every new pain medication that hit the market, but nothing helped much. Eventually she found herself relying on the powerful painkiller Vicodin to get her through the worst days of each month. "I can't tell you how many jobs I had to cancel because I was completely bedridden," she says. "Sometimes, I would spend four days in bed." Her mother had suffered the same symptoms. "I thought this was my lot in life," Lakshmi says.

It wasn't until 2006, after she had to leave a photo shoot because the bleeding and pain overwhelmed her, that her physician sent her for a consult to Dr. Tamer Seckin, a New York laparoscopic surgeon who specializes in endometriosis. After taking her medical history and doing a physical exam, Seckin told Lakshmi that he was fairly confident that her problem wasn't bad cramps but severe endometriosis, a mysterious, painful and destructive condition that affects about 10 percent of all women and may be involved in up to half of all cases of infertility.

Doctors believe endometriosis occurs when bits of the uterus' lining normally dispelled during menstrual periods, somehow ends up in the abdominal cavity. Doctors think this may occur when some of this tissue inadvertently backs up through the fallopian tubes, while others suspect that some women are born with displaced tissue. In some women, these clumps of tissue are able to take root and establish a blood supply and grow outside the

uterus. Like the uterine lining, this tissue is hormone sensitive, so it expands and bleeds with a young woman's monthly cycle. Over time, lesions, scar tissue or adhesions may also form, causing damage to a woman's abdominal, pelvic and intestinal areas, as well as high levels of pain, usually around the time of her period (but not always).

Because few women are familiar with its symptoms and there is no simple screen, it often takes 10 years before an accurate diagnosis is made. Even Lakshmi, who went to top-flight doctors in New York and Los Angeles, was 36 years old before she got her diagnosis. In Lakshmi's case, Seckin suggested laparoscopic surgery to meticulously excise the tissue, a procedure he expected would take about 90 minutes. Instead, it took four hours. "And that was the first of four surgeries," Lakshmi says.

But as more and more of the tissue was excised, Lakshmi said she started to feel better for the first time in decades. "Now I'm a different person," she says. "I hid a lot of my pain for a long time because I thought people would think I was exaggerating. I suspect that even some of the people who are nearest to me proba-

bly felt that way to some degree." The better she felt, however, the more frustrated she became that she'd had to wait so long for effective treatment of such a common disorder, says Seckin. "She posed the same question that many of my patients have raised: Why didn't anyone figure this out about me decades ago? There's so much misunderstanding and confusion. I encouraged her to talk about it, because if she doesn't, who will?"

That thought inspired Seckin and Lakshmi to launch

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the this month. The New York–based group hopes to raise awareness, improve education, press Congress for more research money and lobby medical schools to teach students more about the disorder. They want more women to become familiar with the symptoms, which can include the following: significant pain around the time of menstrual periods that doesn't dissipate once the flow begins; pain that increases during intercourse, urination and/or during defecation; bloating; infertility; and persistent intestinal, pelvic and abdominal pain and discomfort.

Dr. Aaron Styer, a Harvard reproductive endocrinologist who specializes in endometriosis research and treatment, says patients whose pelvic pain is not responding to over-the-counter pain medications and whose quality of life is impacted (intercourse has become painful or many days of work or school are missed) should not assume that they are simply dealing with regular menstrual cramps or PMS. Doctors can use vaginal ultrasound and a physical exam to narrow down which women with pelvic pain are most likely to have it, although the diagnosis isn't considered confirmed until suspect tissue has been surgically excised and biopsied.

Depending on the woman's symptoms and age, some doctors initially treat the condition with a range of pain medications and hormone suppressants. GnRH agonists, the hormone suppressants commonly prescribed, effectively shrinks the tissue, reduces pain and stops menstrual bleeding by shutting off ovarian production of estrogen and creating a drug-induced and temporary menopause. The downside is that many women end up exchanging one set of miserable symptoms for another, as they are plunged into a sudden (and temporary) menopause. Common side effects include hot flashes, vaginal dryness, sleeplessness, headaches and loss of bone density. Styer says there is also very little known about this treatment's long-term safety, particularly for younger women who still want to start families. (Endometriosis stops being a problem once menopause is reached and a woman's periods stop.)

The other problem with drug treatment, adds Dr. Harry Reich, one of the pioneers of laparoscopic surgery who

recently retired after a long practice based in both Manhattan and Pennsylvania, "is that it has never cured anyone." He said that while attempts to subdue the growth of these cells with lasers and other forms of electrical surgery have largely proved disappointing, laparoscopic excision done by a skilled and experienced surgeon, can often prevent the condition from returning. Seckin added that these clean-up surgeries can sometimes help women whose infertility is related to endometriosis get pregnant without in vitro fertilization. "Ten years ago, endometriosis surgeries were looked at as a gimmick," he says. "But now we're getting respect and attention."

But that doesn't mean surgery is without downsides too. Styer says there are relatively few surgeons around the country who specialize in this procedure, and Reich suggests many insurance companies still don't have a diagnosis code for the surgery and may balk at paying. "But women who have not gotten relief by other methods and are really persistent can sometimes get them to cover the surgery," Reich said.

In the meantime, research continues. Studies indicates that up to 80-90 percent of all women eventually have some of this tissue displaced in their pelvic region, Styer says, but only a minority experience problematic proliferation. "We still need to understand what it is about specific patients that allows this tissue to form in the pelvis, to recruit a blood supply and maintain itself over years," he said. While this area of gynecologic medicine has traditionally been underfunded, he says it's getting more attention now, and some of the new stimulus money is being spent on it. Lakshmi says she hopes to tour college campuses for the foundation and encourage women in pain to seek help. "I want to educate other women so they don't have to go through what I went through," she says. "If we could find this earlier, more women could have more productive lives. If you're having bad cramps all the time, you need to go and get this checked out."

*For more information, visit the <http://www.nlm.nih.gov/medlineplus/endometriosis.html>*