Insight and news from Johns Hopkins Medicine

Medical Mysteries
It’s not “all in your head.” Beware of five conditions that cause hard-to-diagnose pain for women
IT’S NOT NEWS that hypertension increases your risk for heart disease and stroke, but new research is discovering it can also increase your risk for kidney disease.

“Hypertension is the second leading cause of kidney disease in America after diabetes,” says nephrologist Deidra Crews, M.D.

Crews and her Johns Hopkins colleagues recently completed a study on the link between high blood pressure and kidney disease, showing that 27.5 percent of people with diagnosed hypertension also suffer from kidney disease. But even more startling is that 22 percent of study participants with previously undiagnosed high blood pressure also suffered from kidney disease.

The message is clear: “If you’re a patient with high blood pressure, ask your doctor to test for kidney disease, too,” Crews says.

And even if you haven’t been diagnosed, know what your blood pressure is. Chronic kidney disease can lead to kidney failure, and even those with pre-hypertension are at risk.

Risk factors for both hypertension and kidney disease include obesity, inactivity and heart disease.
Towers Rising

If you’ve been to Johns Hopkins’ main medical campus during the past two years, you’ve no doubt noticed that the skyline is undergoing a major transformation. That’s because a 1.6-million-square-foot hospital building is nearing completion. Slated to open in early 2012, the new building will present a whole new “front door” for The Johns Hopkins Hospital.

AMONG THE FEATURES ARE:
- Two connected 12-story towers, one for cardiovascular and critical care, one for the children’s hospital
- All-new emergency departments
- All private rooms
- 33 operating rooms for general surgery, cardiac surgery, neurosurgery, pediatrics and obstetrics
To learn more, visit hopkinsmedicine.org/newbuildings.

health insights

HEALTH ADVICE THAT TEENAGE BOYS NEED

TEENAGE BOYS are not receiving sufficient sexual health counseling. According to a new study by Johns Hopkins researchers, only 21 percent of sexually active boys had discussed HIV and other sexually transmitted infections (STIs) with their health care providers.

The problem isn’t merely that boys are more reluctant than girls to ask questions. Lead study author Arik Marcell, M.D., M.P.H., says boys don’t encounter the same health care “triggers” that girls do. “Girls are coming in to see their doctors for contraceptive use and reproductive care,” he says. Boys, on the other hand, don’t typically seek care for their sexual health, and even when they do visit medical facilities their doctors are not initiating the conversations.

Marcell says consistent guidelines are needed for providing sexual health care to boys, and providers need to be trained and comfortable in offering reproductive health services to young men and women.

“I don’t think boys understand the importance of the sexual health visit,” Marcell says. “But there are a core set of services young men should receive, including a review of their sexual histories, screening for STIs and HIV, counseling in STI prevention, a genital exam and making sure all their vaccines are up to date.”

IF YOU'RE EXPECTING a child and wondering how safe it is to continue your exercise routine, a study now under way may provide some answers.

Recently, Andrew Satin, M.D., head of the Department of Obstetrics and Gynecology at Johns Hopkins Bayview Medical Center, was asked to develop exercise guidelines for the American College of Obstetricians and Gynecologists. But because there hasn’t been much research on the subject, he has partnered with a colleague, Linda Szymanski, M.D., and begun a study to monitor 60 pregnant women of varying degrees of physical fitness. Satin says the two goals are to determine a safe level of maternal exercise for women and their fetuses and to develop better techniques for measuring fetal response to exercise.

Although the Department of Health and Human Services currently recommends 2½ hours of moderate exercise per week for pregnant women, these recommendations don’t take into account individual differences in fitness. Satin and Szymanski hope to develop formulas for individual exercise prescriptions.

For now, Satin says, see your physician to determine the best plan for you. “Avoid dehydration,” he adds, “and any activity where you could fall on the uterus or get hit.” He cites downhill skiing and mountain biking as two sports to avoid.

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Do some professions require greater attention to good vocal health?

We’re in a communications-based society, so many people’s jobs involve talking to others. This is especially true for coaches, teachers, journalists, members of the clergy, attorneys, salespeople and, of course, singers and actors. But being able to use your voice is important for everyone.

What lifestyle choices can I make to protect my voice?

Drink lots of water—which lubricates the vocal cords and helps them vibrate better—don’t smoke, and limit excessive yelling and screaming. Speak on full, deep breaths and pause to take a breath before you run out of air. If your voice starts feeling fatigued or rough, your body is telling you to back off on how much you’re using your voice.

What if I still need to talk?

When your voice is feeling rough, speak normally. The worst thing you can do is push or talk louder to compensate for the roughness, which can cause vocal cord damage. Don’t whisper, either. It’s just another way of trying to squeeze out your voice. Use a microphone when addressing large groups, and prioritize your voice use by not talking when you don’t have to.

How do I know if I might have a vocal problem that should be looked at by a doctor?

By definition, anyone whose voice isn’t working the way they’d like it to work has a voice problem. If your voice is rougher or quieter than you’d like it to be, or if speaking requires more effort, then it’s a voice problem. Symptoms might include hoarseness that lasts more than a couple of weeks or that is associated with ear pain, difficulty swallowing or painful speaking. Even if you don’t have symptoms, have your voice evaluated and treated if it is keeping you from living your life.

VISIT OUR VOICE CENTER

For more information, appointments or consultations, call 800-547-5182 or visit hopkinsmedicine.org/voice.
IT’S COMMON KNOWLEDGE that being overweight is a controllable risk factor in a host of health problems. And if you’re keeping score on those problems, you can add one more, and it’s a biggie: metabolic syndrome.

Metabolic syndrome is a cluster of risk factors that can significantly increase your odds of developing type 2 diabetes, heart disease, stroke or peripheral artery disease.

“It’s like a big stop sign that says you need to stop what you’re doing and rethink what’s going on with your health,” says Johns Hopkins endocrinologist Annabelle Rodriguez, M.D. “Our goal is to find people well before they develop diabetes or cardiovascular disease. Metabolic syndrome gives people plenty of warning signs, which are strongly linked to being overweight and obese.”

No one likes admitting they’re overweight, but it’s a critical conversation to have with your doctor. Begin by measuring your waist circumference, which should be 40 inches or less for men and 35 inches or less for women. Also, check your body mass index (BMI), which uses your height and weight to measure body fat. Aim for a BMI of less than 25.

The numbers won’t lie. If they tell you that you’re overweight, it’s time to take action.

“Acknowledge the truth,” Rodriguez says, “and get appropriate nutrition counseling, targets for weight loss and exercises that are age-appropriate and customized for whatever medical issues you may have.”

Although it’s important to manage all the risk factors of metabolic syndrome, which may require some medication, getting to a healthy weight is at the top of the list. Losing weight often returns blood pressure, blood glucose and cholesterol to normal levels, which may eliminate the need for medication.

“You have to commit the time and discipline to a new way of eating and exercising, which isn’t easy,” Rodriguez says, “but weight loss can help tremendously in reducing your risk factors for metabolic syndrome.”

CURRENT CRITERIA FOR DIAGNOSING METABOLIC SYNDROME ARE THE PRESENCE OF THREE OR MORE OF THESE RISK FACTORS:

- A large abdomen
- High blood pressure, even if it’s being treated
- Elevated fasting blood glucose
- High triglycerides (a type of fat in your body)
- Low HDL cholesterol (the “good” or “healthy” kind)

What’s more, Johns Hopkins researchers like Annabelle Rodriguez, M.D., continue uncovering additional warning signs of metabolic syndrome, such as low male hormone levels in men.
DOMICA MARTIN, A FORTY-YEAR-OLD mother of three from Fairfax, Va., knew something was wrong. A dull and aching pain in her lower abdomen lurked throughout the day as she cleaned the house, cared for her children and trained for her next marathon. At first, she chalked it up to a pulled muscle.

"Then at times I'd buckle over," she says. "It hurt so bad."

Little did she know, but Martin was about to embark on a medical mystery tour—a journey from physician to physician as she sought relief from chronic pelvic pain, which strikes an estimated one-third of all women at some point in their lives. The condition can be tricky to diagnose, and many of its sufferers are told the problem is “all in their heads,” according to the Society of Interventional Radiology.

JOHNS HOPKINS IS RANKED NO. 1 IN GYNECOLOGY BY U.S. NEWS & WORLD REPORT

For more information, visit hopkinsmedicine.org/womenshealth. For appointments and consultations, call 800-547-5182.

It’s not “all in your head.”
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MEDICAL Mysteries

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“A typical patient I treat is a woman who has gone from physician to physician looking for solutions as she suffers a long, long time,” says Kelvin Hong, M.D., a Johns Hopkins interventional radiologist specializing in pelvic congestion syndrome.

Pelvic congestion syndrome is one of several conditions that leave women with pain that is hard to explain—and diagnose. Here is your guide to five women’s ailments that can be dismissed too easily.

**Pelvic Congestion Syndrome**

**Symptoms:** A dull and aching pain that lingers in your lower abdomen and lower back.

“There also can be a burning sensation or feeling of fullness in the pelvis that worsens with standing and gets progressively worse throughout the day,” Hong says. “The feeling improves when a woman lies down or gets off her feet.” For many women, the pain worsens after intercourse and during menstrual periods or pregnancy.

**The culprit:** Like varicose veins in the legs, valves in the veins of the pelvis become weakened and don’t close properly. Instead of defying gravity and returning blood to the heart, the valves allow blood to flow backward and pool in the veins, causing pressure and bulging.

**Mistaken identities:** Premenstrual syndrome, perimenopause, stress or an occupational problem caused by standing too long. It even hides during diagnostic tests. Once a woman lies down for a pelvic exam or ultrasound, the change of posture relieves pressure on the ovarian veins, which no longer bulge with blood as they do when she stands.

**How it’s treated:** Interventional radiologists like Hong perform an outpatient procedure called embolization while patients are lightly sedated. During the procedure, the radiologist inserts a thin catheter that’s about the size of a strand of spaghetti into the groin’s femoral vein and moves it to the affected vein using X-ray guidance.

“We essentially obliterate abnormal veins,” Hong says, “which forces the blood back via veins that have normally functioning valves.”

Patients can return to normal activities immediately after treatment. Depending on the severity of the symptoms, other treatment options include prescription pain relievers; hormones, such as birth control pills; and surgical options, including a hysterectomy with removal of ovaries, and tying off or removing veins.

**Sphincter of Oddi Dysfunction**

**Symptoms:** It’s like a bad case of déjà vu. After surgery to remove an ailing gallbladder, the same pain strikes again: persistent or recurrent discomfort in the upper right or middle part of the abdomen that radiates around to the back.

“Patients often say the pain is made worse by fatty foods,” says Anthony Kalloo, M.D., director of Johns Hopkins’ Division of Gastroenterology and Hepatology.

Forging a successful partnership with a physician takes time. What can you do to make the most of your all-important first visit to a medical specialist? Here is a handy checklist of what to bring:

- Your referral, if your insurance requires one.
- Your health insurance identification card.
- Your medical chart, including test results, from your referring physician.
- Studies related to your condition, such as blood work and medical images.
- The bottles of medication you’re taking or a list, including name of the medication, if it’s a generic substitution, the dosage, how often you take it, and any special directions such as “take with food.”
- A list of important contacts, including emergency names and phone numbers.
- A list of questions you have about your medical care, including your diagnosis and treatment.
- A notebook and pen so you can write down important information.

It’s easy to feel overwhelmed if you’re faced with a frightening diagnosis or must choose from a variety of confusing treatment options. Seeking a second opinion can help. But what if you live far away can’t travel or have problems with mobility? The good news is, you can get a remote second opinion from the experts at Johns Hopkins Medicine. Specialists in the fields of otolaryngology, gastroenterology, hepatology, neurology, neurosurgery, urology, pathology, gynecology and urogynecology can work with you to provide recommendations about your treatment plan or options. To find out more, visit hopkinsmedicine.org/second_opinion.
The culprit: A small muscle at the end of the bile duct becomes dysfunctional.

Mistaken identities: Irritable bowel syndrome or ulcer disease.

“I’ve seen women who once were told it was because of stress or problems with their marriage,” Kalloo says. “Some were even seen by psychiatrists because they thought the pain was all in their heads. These women had their gallbladder out, so their problem should have been solved.”

How it’s treated: Kalloo says prescription medications, such as calcium channel blockers and long-acting nitrates that relax smooth muscles, offer short-term relief. Also, he says, an endoscopic procedure called a sphincterotomy helps the majority of patients.

Ovarian Cancer

Symptoms: Bloating or swelling of the abdomen, pelvic pressure or stomach pain, trouble eating or feeling full quickly, and having to urinate often or feeling as if you have to go right away.

The culprit: Cancer that begins in the ovaries and reproductive glands.

Mistaken identities: With its vague symptoms, ovarian cancer can easily hide under various disguises—gastrointestinal upset, weight gain or urinary tract infections—says Robert Giuntoli, M.D., a gynecologic oncologist with Johns Hopkins.

Vulvodynia

Symptoms: Pain and burning, stinging or rawness in the vulva make a woman’s life miserable.

“The pain and burning are often worse with contact to the area, so even sitting, wiping and being intimate can be painful,” says Johns Hopkins physical therapist Laura Scheufele. “In extreme cases, I’ve seen women who couldn’t work or whose marriages broke up because of the condition.”

The culprit: Its exact cause remains unknown, but experts have ruled out active infections and sexually transmitted diseases.

Mistaken identities: Urinary tract infection, yeast infection or vaginitis.

How it’s treated: Drug therapy to block pain signals, and occasionally nerve blocks. For women who have pelvic floor muscle spasms or weakness, physical therapy and biofeedback can be helpful, Scheufele says.

Interstitial Cystitis, or IC, also known as painful bladder syndrome

Symptoms: Nagging pelvic pain, pressure or discomfort in the bladder and pelvic region, along with a need to urinate often and with a feeling of urgency.

The culprit: The exact cause remains a mystery.

Mistaken identities: Urinary tract infection.

How it’s treated: A combination of medication, physical therapy and eliminating trigger foods in the diet.

Normal Again

For almost two years, chronic pelvic pain put a damper on Domica Martin’s zest for life, yet she never gave up hope. At last, through her own Internet sleuthing, she made a discovery that would finally solve her medical mystery. Search results kept pointing her to new research by Johns Hopkins. She made an appointment with Kelvin Hong, who quickly diagnosed her condition—pelvic congestion syndrome—and provided successful treatment.

“Life is normal again,” Martin says with relief. And as she trains for her next big race, she knows feeling normal is something no one should take for granted.
Dealing with cancer is a scary roller-coaster ride, especially when you look over the edge. But I’m living proof that it can come to an end. Four months after bladder surgery, I was back to motorcycling with friends. That’s the message I have as a mentor at Johns Hopkins for newly diagnosed cancer patients: There is life after cancer.

I had to deal with it four times. It was my urologist who gave me the diagnosis of noninvasive bladder cancer, which is slow-growing but tenacious. The first two times the tumor was removed, it came right back. After the third time, plus six months of chemotherapy and radiation, my CT scans were clear for 3½ years and I thought I’d beaten it. But then it came back again on New Year’s Eve in 2002.

I needed to have my bladder removed, my doctor told me, because if the tumor escaped my bladder wall I’d be dead. He referred me to Mark Schoenberg, M.D., head of urologic oncology at Johns Hopkins, who was doing six of the surgeries every week. He’s one of the best in his field. I’ve been cancer-free ever since and there’s nothing I can’t do now that I could do before. I’m 63 and I’m back to motorcycle trips and remodeling my house.

As a volunteer mentor, I tell patients and their families what to expect. Family members can be more shaken up than patients, which was true for my wife and kids. I stay away from giving medical advice. As Dr. Schoenberg told me, “I can tell patients all about the surgery and recovery, but I can’t tell them what it feels like.” I think it eases their anxiety just seeing that I’m healthy after all I went through.

In His Own Words
Watch a video featuring Steve Winick telling his story at hopkinsmedicine.org/mystory. For more information about bladder cancer, visit urology.jhu.edu/bladder. For appointments and consultations, call 800-547-5182.

BLADDER BASICS

• The only symptom that prompted Steve Winick to seek a diagnosis was blood in his urine, which is the most common first symptom of urinary bladder cancer.

• His three encounters with noninvasive urothelial carcinoma, the most common form of bladder cancer, required tumor removal through a urethral tube. The final recurrence was muscle-invasive, requiring a radical cystectomy to surgically remove his bladder.

• Winick is a Caucasian man, the highest bladder-cancer risk group, but at age 50 when he was first diagnosed, he was far younger than the average age of 73.
If you’ve recently been diagnosed with cancer, it’s wise to ask for a second opinion on your pathology specimen.

Johns Hopkins researchers with the Urological Pathology Consult Division, led by Jonathan Epstein, M.D., first reported on biopsy errors a decade ago, when they found a margin of error in prostate cancer diagnoses large enough to give them pause. According to the study, one in every 600 diagnoses showed mistakes.

“This study only addressed major changes in diagnoses, such as a diagnosis of cancer being reversed to no cancer,” says Johns Hopkins pathologist George Netto, M.D. “It didn’t look at changes of grading of the cancer.”

The chances for some type of modification based on a second opinion are even greater than the study indicated.

“Asking for a second opinion could lead to a significant change in surgical or medical intervention,” Netto says.

Even if the diagnosis error isn’t catastrophic, such as advising a patient that he has cancer when he really doesn’t, an error in grading can be consequential. Netto points to prostate cancer as an example: If your diagnosis changes from a higher grade to a lower grade cancer, it could mean having the option to avoid radical treatment.

Seeking second opinions is becoming standard practice, and it is mandatory at Johns Hopkins. Last year, Epstein’s lab reviewed the pathology reports of 30,000 cases in which patients requested second opinions.

Netto says patients should be proactive in requesting that doctors take another look.

“A second opinion can reverse the diagnosis in up to 5 percent of cases for some types of cancers,” he says, “like those of the breast and pancreas.”

The margin of error is 1.4 percent, which is equivalent to 30,000 cancer diagnosis mistakes annually in the U.S.

Of 6,171 biopsy slides sent since late 2008 for a second review at Johns Hopkins, pathologists disagreed with the diagnosis on 86 of them.

6 cancers that are the toughest to diagnose are prostate, bladder, head and neck, soft tissue, skin and lymph system.

For more information about pathology second opinions, visit pathology.jhu.edu or call 800-547-5182.
The Johns Hopkins Hospital has been consecutively ranked the No. 1 hospital in America by U.S. News & World Report for 20 years. hopkinsmedicine.org/usnews

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- Johns Hopkins Medicine International
  - (Overseas and non-English-speaking residents)
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