

HEALTH ■ A women's bladder ailment finally gets some notice

■ It's not a new disease, but it's one that's been overlooked. As many as 450,000 Americans, mostly women, are affected. And the symptoms, at least if you're the patient, can't be ignored: Tormenting pain, accompanied by the incessant urge to urinate—sometimes up to 60 times a day. Understandably, the victims are hollow-eyed from lack of sleep. During the day, they dare not wander too far from a bathroom. To add to their woes, those who fail to respond to treatment are often told that the problem is in their head.

The disease is interstitial cystitis (IC)—a chronic inflammation of the bladder—and it is finally getting some attention. Last month, specialists from around the world gathered at the National Institutes of Health in Bethesda, Md., to attend the first scientific conference on the subject. The federal government, moreover, has just begun funding research for an IC cure. "It's been a long, uphill battle to change medical opinion," says Dr. Vicki Ratner, a 37-year-old orthopedic resident at Montefiore Medical Center in New York and a leader in bringing IC to light.

"Relieve the stress"

Ratner was introduced to IC not as a doctor but as a patient. At age 32, while a medical student, she woke one morning feeling, she says, as if her bladder "was on fire." Antibiotics didn't work. Desperate for help, Ratner saw 14 specialists, from allergists to urologists. When a battery of tests revealed nothing, she was advised to get counseling or quit her medical studies "to relieve the stress." In the end, Ratner diagnosed herself. While she was leafing through medical journals for clues, a summary in a paper about IC jumped off the page. "Before I finished reading the abstract," she says, "I knew that's what I had."

Convincing her urologist was another matter. While IC has been known to medicine since 1830, it was considered a rare disease of elderly women. Moreover, verifying the diagnosis is somewhat risky. Patients must undergo cystoscopy—the insertion of a long, thin viewing instrument into the bladder under general anesthesia. Ratner insisted on having it done, despite her doctor's reluctance. Sure enough, the lining of her bladder was covered with tiny hemorrhages and scar tissue—one of IC's telltale signs.

Just what triggers IC is still a mystery. At the NIH conference, Dr. Philip Hanno of the University of Pennsylvania downplayed theories that suggest a viral or bacterial culprit. The causative agent, according to Hanno, "is more

In pain, sleepless—and ignored

likely to be a defect in the wall of the bladder, or alternatively, some substance in the urine that irritates the wall of the bladder." Hanno is skeptical of the cookbooks popular among IC sufferers. The diets recommend avoiding



Dr. Vicki Ratner and a deskful of mail for the Interstitial Cystitis Association, which she founded

caffeine and such low-acid foods as tomatoes and oranges. "They're not based on anything scientific," he warns.

Like many diseases, the severity of IC varies. About 50 percent of patients will experience brief remissions. But some patients suffer such unrelenting pain that they simply cannot function. A recent national survey by Philip Held of the Urban Institute in Washington, D.C., found that IC victims are nearly four times likelier to have contemplated suicide than the general population; 50 percent cannot hold full-time jobs, and 63 percent have painful intercourse. IC patients also ranked

their quality of life below that of kidney-dialysis patients. "That was a surprise," says Held, "given how awful life under dialysis is perceived to be."

A helping hand

In the four years since her diagnosis, Ratner has crusaded to raise popular awareness of the disorder. A brief appearance on "Good Morning America" generated 10,000 letters, and inside 1 hour the producers of the show received 400 phone calls. Says Ratner: "Most of the people who responded thought that they were the only person in the world with this problem."

To spare others some of her ordeal, Ratner founded the Interstitial Cystitis Association in 1984. It serves as both an information and a support group, and now has chapters in every state. (Contact the ICA at P.O. Box 1553, Madison Square Station, New York, N.Y. 10159, or P.O. Box 151323, San Diego, Calif. 92115.) There is still no cure, but various treatments can alleviate some of the symptoms. Ratner herself has gotten relief for several months at a time from the anti-inflammatory drug DMSO. Other patients have benefited from a procedure known as hydraulic distention. This entails stretching the bladder by injecting fluid to help break up the scar tissue. Still other patients have gotten help from Elmiron, an experimental oral drug. It is believed to coat the bladder wall, protecting it from irritating substances in the urine. Because it is not yet known whether the drug

could harm a developing fetus, pregnant women are advised against taking Elmiron. In some patients, the drug can also trigger allergic reactions such as skin rashes, watery eyes or sneezing. Painkillers and sleeping pills, while no long-term solution, can make life more tolerable, but addiction is always a risk.

Most patients cope by relying on a heavy dose of determination—and pragmatism. "I lead as full a life as possible," says Ratner, who is about to complete her surgical residency. "But I always know where the next bathroom is." ■

by Kathleen McAuliffe