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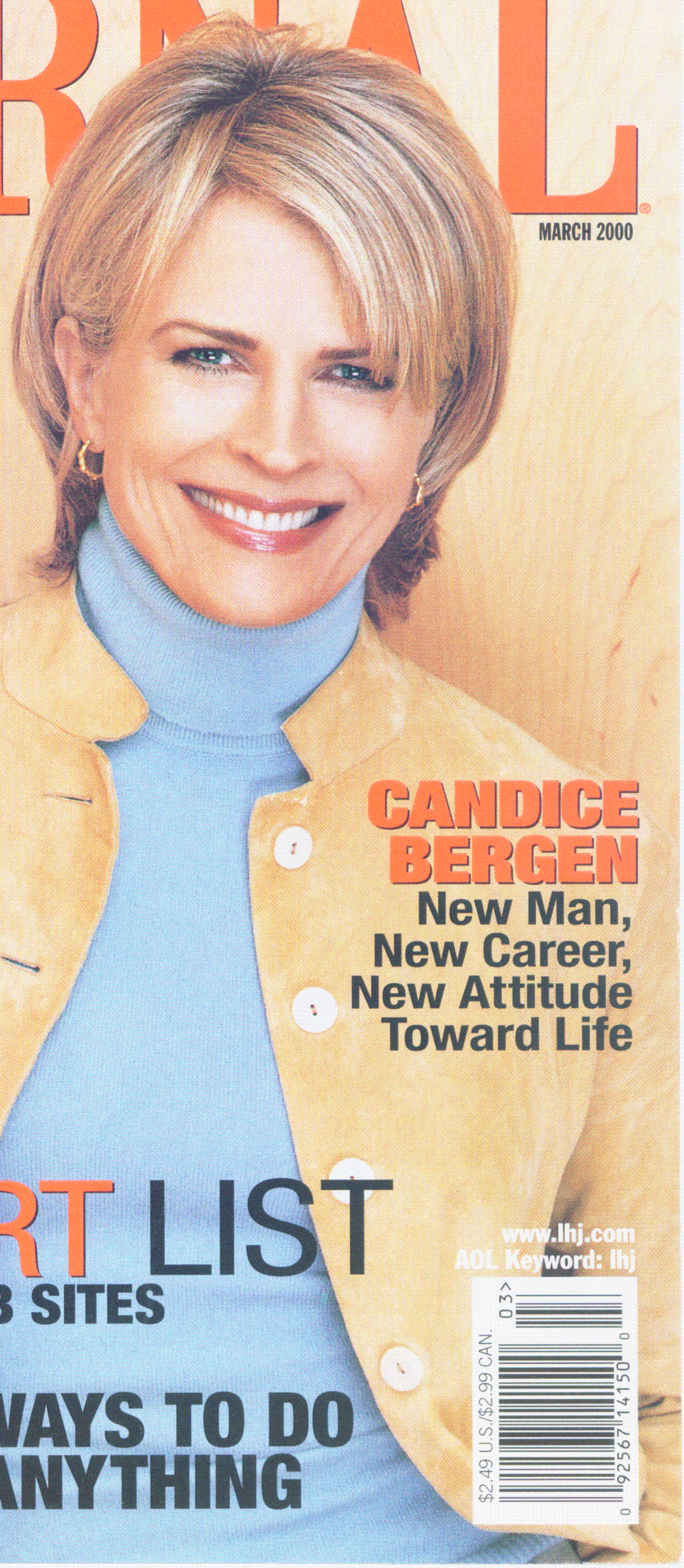

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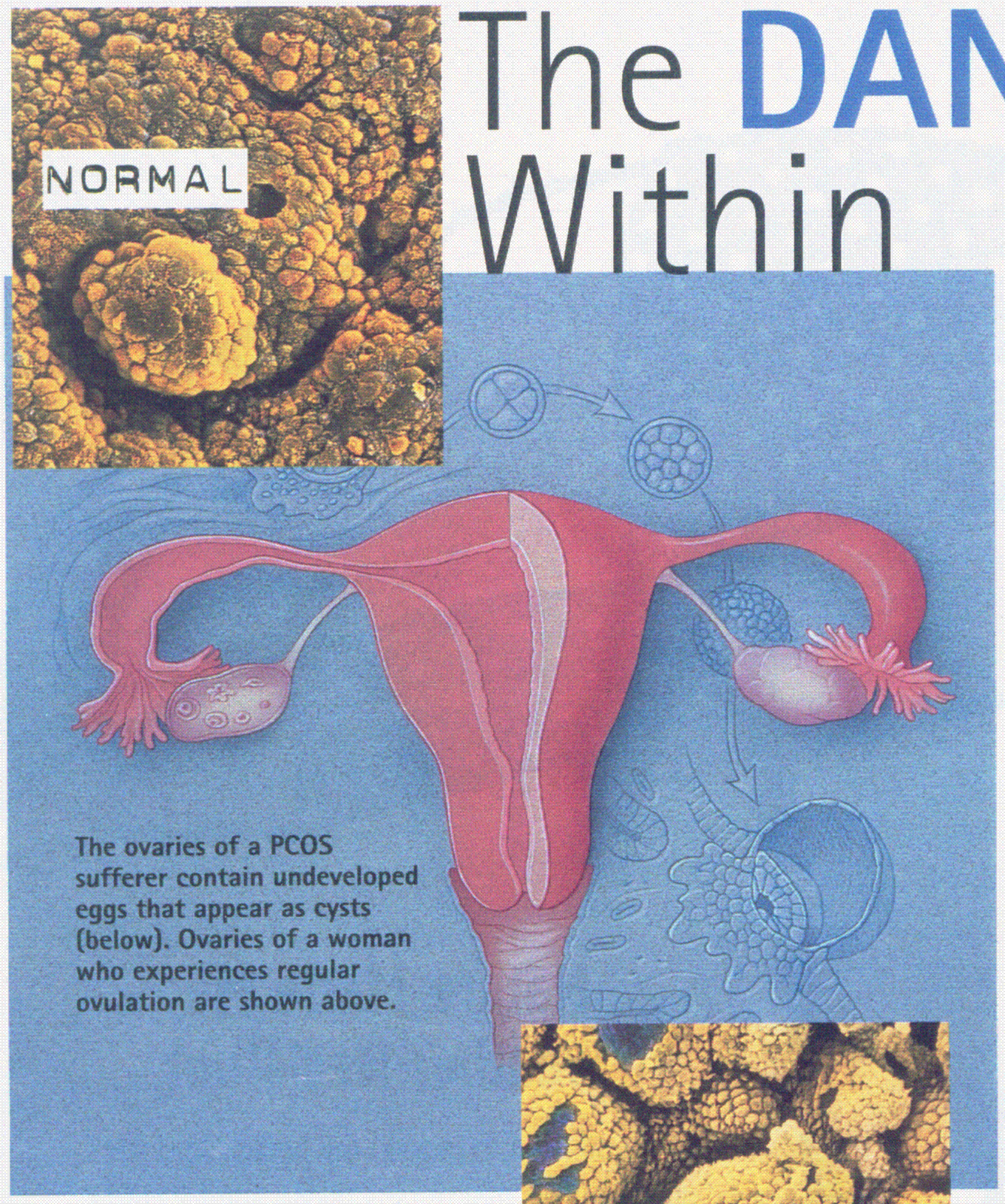
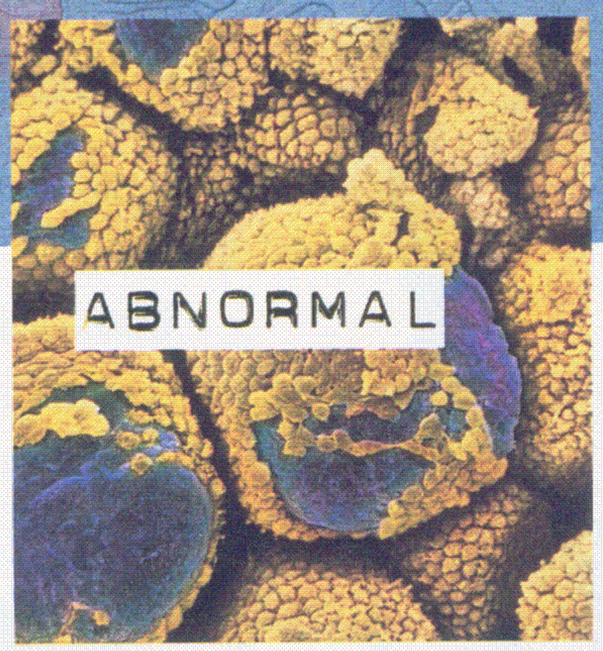
The DANGER Within



The ovaries of a PCOS sufferer contain undeveloped eggs that appear as cysts (below). Ovaries of a woman who experiences regular ovulation are shown above.



It's the leading cause of female infertility. As many as five million U.S. women have it. Could you be at risk for Polycystic Ovary Syndrome?

By Kathleen McAuliffe

Beth Kushnick's problem began during puberty. Her friends got their periods; she didn't. During her late teens, her weight shot up by forty pounds. When she finally began to menstruate, her periods were long and heavy; then she'd go for six months at a stretch without one. Her twenties were just as bad: She was plagued by constant fatigue and tender and bloated ovaries.

Kushnick, now thirty-nine and working in the film industry in New York, knew something was wrong. But visits to two gynecologists and two endocrinologists provided no answers. "Basically," she says, "I was put on the Pill to regulate my periods and sent on my way."

Frustrated, Kushnick took action, contacting women's health organizations and combing medical libraries for clues. She finally deduced she was suffering from Polycystic Ovary Syndrome (PCOS), a hormonal and metabolic condition. After five years of searching, she discovered the National Organization for Rare Disorders, in New Fairfield, Connecticut, which put her in contact with other women who shared similar symptoms. "What a relief it was to find out I wasn't alone," says Kushnick.

Though many women have never heard of it, PCOS affects as many as five million women in the United States (or one in ten), and is the leading cause of female infertility. It is, says Kushnick, "absurdly out of place on a list of rare disorders." Left untreated, it can cause life-threatening complications.

PCOS was first recognized more than sixty years ago (and initially was called Stein-Leventhal syndrome after the two doctors who discovered it). But it is a complicated condition frequently overlooked by physicians. Generic symptoms are part of the problem. Erratic periods, acne, hirsutism (excess hair on the face and body), and balding on the crown of the head—caused by elevated levels of male hormones—are common. Sixty percent of women with PCOS are overweight. All of these symptoms, however, can be caused by other disorders.

And to complicate matters, not all cases look alike: One woman's symptoms may scream PCOS—obesity, raging acne, heavy facial hair. Another patient—a woman of normal weight whose only complaint is a longer-than-normal menstrual cycle—may be more difficult to diagnose. Even the symptom that gives the disorder its modern *(continued)*

PHOTOS, FROM TOP: PROF. P. MOTTA/CUSTOM MEDICAL STOCK PHOTO, MARCIA HARTSOCK/STOCK SHOP/MEDICHROME, PROFS. P. M. MOTTA AND S. MAKABE/CUSTOM MEDICAL STOCK PHOTO.

THE DANGER WITHIN
Continued

name—undeveloped eggs in the ovaries that appear as multiple cysts in ultrasound images—doesn't affect every woman with PCOS.

"In my experience, as many as half of women walking around with PCOS don't know it," says Roger A. Lobo, M.D., chairman of the department of obstetrics and gynecology at Columbia University College of Physicians and Surgeons, in New York City.

Sometimes a patient with PCOS is diagnosed in her teens—perhaps by a gynecologist who's able to piece together disparate symptoms, or by a dermatologist who's "particularly aware of what male hormones can do to the skin," explains Walter Futterweit, M.D., a clinical professor of medicine in the division of endocrinology at Mount Sinai School of Medicine, in New York City. Other women don't discover they have PCOS until they have trouble conceiving a child.

But new research suggests that PCOS is much more than just a fertility problem. Scientists have discovered that women with the disorder are unable to use insulin efficiently. "PCOS is a metabolic disturbance with far-ranging health effects, increasing a woman's risk of diabetes, heart disease and endometrial cancer," says John Nestler, M.D., professor of medicine and chairman of the division of endocrinology and metabolism at Virginia Commonwealth University, in Richmond.

Fortunately, once diagnosed, the disorder can be controlled. Mild cases can be managed with appropriate diet and exercise to help correct the metabolic problem at its root. Drugs have proved effective in helping to regulate the menstrual cycle, counter excess hair growth, even to restore fertility.

Being informed is the key. There are more resources for the disorder now than when Kushnick was looking twelve years ago—thanks, in part, to a growing network of PCOS women. "I started chatting with them over the phone, and followed up with packets of medical literature I'd

collected about PCOS," says Kushnick. Soon she was overwhelmed with requests.

Today, she heads the PCOS support group of the American Infertility Association, a nonprofit organization based in New York. Last October, she chaired a conference to educate patients on PCOS at Mount Sinai.

Doctors need to be informed, too. "Traditionally, reproductive disorders have not been part of general medical training," says Andrea Dunaif, M.D., an internist endocrinologist specializing in reproduction at Brigham and Women's Hospital, in Boston. "A lot of obstetricians, gynecologists and internists tell PCOS women they're too fat, put them on the Pill, and that's it. There's often a lack of appreciation of the long-term consequences."

ARE YOU AT RISK?

Though the underlying cause of PCOS remains a mystery, medical researchers believe that insulin resistance sets off a chain reaction that throws hormones out of kilter. As the disorder progresses, certain cells in the body grow less responsive to insulin and blood-sugar levels climb, which causes the pancreas to step up insulin production. In turn, the excess insulin stimulates the ovaries and adrenal gland to churn out testosterone and other androgens, which can disrupt ovulation. Depending on a woman's sensitivity to male hormones, she may develop acne and male-pattern hair growth or loss. Failure to properly utilize insulin also can slow metabolism, which helps explain why so many PCOS women are overweight, says Dunaif. At the same time, she notes, it's likely the male hormones increase appetite.

But that's not the worst of it. A PCOS woman continues to produce estrogen, but stops manufacturing progesterone. This imbalance causes the lining of the uterus to continue thickening, a condition that can invite endometrial cancer. Estrogen also stimulates the pituitary gland to release luteinizing hormone (LH), which signals the ovaries to release an egg. In normal functioning, after the egg is released, levels of LH drop; in women with PCOS, they remain elevated.

PCOS can culminate in diabetes and cardiovascular disease. Women with the disorder tend to have low HDLs (good cholesterol), high LDLs (bad cholesterol) and elevated triglycerides—factors that make them prime candidates for heart attack and stroke.

Experts advise any woman with an irregular menstrual cycle to be evaluated for PCOS. Family history of the disease is also a risk factor. In a study of around one hundred families, Dunaif found that 50 percent of sisters of PCOS women either have the disorder or show signs of it.

A DIFFICULT BALANCING ACT

Because the range and severity of symptoms vary enormously, no treatment fits all patients. If the woman is overweight, doctors first recommend lifestyle changes—regular exercise and a low-calorie, low-carbohydrate diet. Slimming down can help restore fertility and lower male hormone levels for some patients, experts say.

Long a mainstay of PCOS therapy, oral contraceptives are still used to regulate periods and suppress excess male hormones, which can clear acne and alleviate hirsutism. More important, they reduce the risk of endometrial cancer. (Women with PCOS should avoid forms of the Pill that contain a progestin called Levonorgestrel, which mimics male hormones, potentially worsening symptoms.) Spironolactone is commonly prescribed with *(continued)*

FOR MORE INFORMATION

To learn more about Polycystic Ovary Syndrome, contact the American Infertility Association, 666 Fifth Avenue, Suite 278, New York, NY 10103; 888-917-3777; *www.americaninfertility.org*

the Pill for its anti-androgen properties, which help to manage severe hirsutism and replenish hair on the head. (Women who are or plan to become pregnant should not take spironolactone.)

But the latest approach to PCOS therapy is drugs—such as Glucophage and Rezulin—that treat the insulin resistance believed to be at the core of the disorder. Glucophage can help patients lose ten to fifteen pounds, and both drugs lower testosterone levels, which decreases acne and hirsutism. The medications have also been shown to reduce circulating levels of LH and insulin—changes that experts hope may translate into increased protection against diabetes and heart disease.

Once diagnosed, PCOS can be controlled. Drugs are effective in helping to regulate the menstrual cycle and restore fertility

Finally, Glucophage and Rezulin frequently restore ovulation. In clinical trials of Glucophage, PCOS women who'd been unable to conceive by any other method got pregnant.

Another approach for PCOS sufferers unable to conceive is the fertility drug clomiphene citrate (Clomid, Milophene or Serophene). If three cycles of the medication fail to induce ovulation, the next step is injections of gonadotropin, which are pituitary hormones that regulate ovulation.

Because those with PCOS may be at higher risk than others for complications of fertility treatments—multiple births, miscarriage and ovarian hyperstimulation, a potentially life-threatening condition—they should choose fertility specialists with expertise in treating these conditions.

"My doctor was very conservative, stepping up the dose of the fertility drugs in tiny increments to avoid serious side effects," says a thirty-five-year-old PCOS patient who requested anonymity. The cautious approach paid off. After three rounds of Clomid and four rounds with gonadotropin, her pregnancy was complication-free, and she now has a healthy two-year-old girl. Her success story is not unique: The vast majority of PCOS women can have a baby with fertility therapy.

The latest development is an experimental drug, INS-1, an insulin-sensitizing agent similar to Glucophage and Rezulin, that has shown promising results in clinical trials. After six to eight weeks on the drug, 86 percent of PCOS patients ovulated, compared with 27 percent of women in the placebo group, according to a study reported last April in *The New England Journal of Medicine*. And no side effects were reported.

LIVING WITH PCOS

Even with treatment, having PCOS can be an ordeal. The most distressing aspect, according to a survey of patients, is the disorder's visible markers, which can be especially devastating for young women.

"Freakish" is how a thirty-nine-year-old Sacramento-based journalism student describes her early twenties, when PCOS threw her a quadruple whammy: Her weight ballooned, and she developed acne, facial hair and bald patches on the crown of her head.

Lacking medical insurance, she went to the California Department of Health Services, which refused to cover electrolysis. She was able to get another state agency to cover four hundred hours of facial electrolysis, and she no longer endures the indignity of a beard.

For now, PCOS's effects aren't easily erased, but most sufferers agree that education and emotional support can help. "The feeling of solidarity is so empowering," says Kushnick. ■

Kathleen McAuliffe is a frequent contributor to Ladies' Home Journal.