

“My breasts wouldn't stop growing”

WITHIN WEEKS SHATSI RABIE WAS TRANSFORMED FROM AN ACTIVE MOM-TO-BE INTO THE VICTIM OF A HORRIBLE DISFIGURING DISORDER. FOR THE FIRST TIME SHE SHARES HOW SHE RECLAIMED HER BODY—AND HER LIFE.

BY CYNTHIA HANSON

One morning during the second trimester of her first pregnancy, Shatsi Rabie awoke to find that something strange had happened: She had gained three pounds overnight—and the weight seemed to have gone right to her breasts. Shatsi shrugged it off, reasoning that her pregnancy pounds were simply creeping on a little earlier than expected.

But as the weeks wore on, her breasts continued to grow at an alarming rate. By the sixth month of her pregnancy, five-foot-ten Shatsi, who weighed 150 pounds when she conceived, had ballooned to 230. Her breasts had expanded from size 38C to a massive 44KKK; they fell into her lap when she was sitting and covered her face when she was lying down. And her nipples leaked milk at night, soaking her pajamas and bed linens.

“I was too depressed to look in the mirror, because the person in the mirror wasn't me,” recalls Shatsi, now 30. “I wasn't eating enough to make my breasts get huge. I knew something was drastically wrong.”

(continued)

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But what? It wouldn't be until Shatsi was six weeks postpartum—and still suffering—that she would learn the truth: Her body was being held hostage by a mysterious disorder called gestational gigantomastia, which causes rapid immense growth of the breasts and excessive lactation during pregnancy. Gigantomastia is so rare, in fact, that most doctors have never even heard of it—and the few who do treat this disfiguring disease are unsure of its precise cause.

Today Shatsi weighs 165 pounds and wears a 36C bra. To see her sporting chic black capri pants and a snug-fitting turquoise top, it's hard to picture her as she was three years ago: "I was a giant walking ball."

On a mild February afternoon, Shatsi is sipping coffee while sitting on a black chenille sofa in the spotless apartment she shares with her second husband, Youssef Ajaoui, 25, in suburban Metairie, LA. Her two sons from her first marriage, 6-year-old Samir and 4-year-old Omar, are visiting her parents in her native Egypt, where she owns a residential construction company and frequently travels to conduct business.

For all her suffering, Shatsi, a dark-haired beauty with charcoal eyes and a warm smile, is remarkably matter-of-fact as she recounts her battle with gigantomastia. She agreed to discuss her medical nightmare so she could raise awareness of a bizarre disorder that robs women of their mobility, distorts their appearance, and is frequently undiagnosed or misdiagnosed. As she says, "I don't want anybody to go through what I did."

A LIFE INTERRUPTED

At 23, Shatsi felt life was full of possibility. She had just married her college sweetheart, a graduate assistant whom she met while studying business administration at Cairo University, and together the couple enrolled in the M.B.A. program at Emporia State University in Emporia, KS. (Shatsi won't disclose her now ex-husband's name; in this story he's referred to as Roni.) When Shatsi became pregnant unexpectedly later that month, she was thrilled. "I always liked babies," says Shatsi. "In my culture it's not unusual for a woman to have a baby at [that age]."

Her first trimester was blissfully free of morning sickness, fatigue, or bloating. With energy to spare, she decorated the apartment, volunteered at nursing homes, kept up with her studies, and socialized with classmates.

Then, in her fourth month, the nightmare began. She couldn't buy bras fast enough to keep up with the growth of her breasts, and her nipples stretched to three and a half inches in diameter. Meanwhile the skin on her nipples, her breasts, the back of her neck, and her underarms turned dark brown and black. "I thought, My God! It looks like I've never taken a shower in my life," she recalls. "I rubbed it with alcohol, but it wouldn't come off."

Shatsi's doctor, a family practitioner who also delivered babies, had never seen a patient with her condition. "Her breasts were the size of small watermelons," says John Bernard, who now practices in Topeka. Stumped for an explanation, he ordered blood tests; the results were normal, so he told Shatsi her body was having an extreme response

to pregnancy and that she'd slim down after her baby was born. In the small Kansas town where she lived, Shatsi didn't have access to a medical specialist for a second opinion. She accepted Bernard's diagnosis, hoping he was right.

Shatsi's size made daily life a challenge. Her breasts were so large that she couldn't bend over to tie her shoes, so she wore slippers. Her knees hurt when she climbed stairs, and she couldn't stand for more than five minutes, because the weight of her breasts caused excruciating back pain. At school she sat in a chair without arms because she couldn't fit into standard-issue classroom seats with attached desks.

Even sleeping brought her no comfort. "If I moved from one side to the other, I'd have to move my breasts first," explains Shatsi, who had enjoyed playing tennis, swimming, and horseback riding before she became pregnant. "So I slept sitting up. But I never got a good night's sleep."

Too large for maternity clothes, Shatsi shrouded herself in shapeless oversize outfits. For the first time she knew what it felt like to live in a society that scorns the obese. "I was depressed and humiliated," says Shatsi. "Can you imagine the stress of going from being a woman

COULD IT HAPPEN TO YOU?

Gigantomastia strikes without regard for race, ethnicity, breast size, or body type. While not associated with breast cancer, the condition can be fatal if the breasts reach 40 to 100 pounds, because the skin may split, causing uncontrollable bleeding.

For decades reduction surgery was the only way to control the disorder, and since regrowth is common, many patients who had this treatment eventually underwent mastectomies. In recent years several drugs have been used to arrest breast growth, including Parlodel, pergolide, and tamoxifen; but tragically, doctors unfamiliar with

the condition and therapy alternatives still may prescribe mastectomies.

There are four variations of the disorder, each linked to hormone sensitivity. "It's still a mystery as to what triggers that sensitivity," says H. Randall Craig, M.D., who explains that this shocking condition can strike:

AT PUBERTY This is the most common form of the disorder, and it can be hereditary. It affects some 1,800 girls in the U.S. every year at the onset of menstruation.

IN PREGNANCY Gestational gigantomastia affects one in 100,000 pregnancies in the United States every year. The baby's growth

may be stunted when nutrients are diverted to support the growing breast tissue.

FROM MEDICATION

Although exceedingly rare, gigantomastia has been reported in women who've taken the antibiotic Neothetazone (for tuberculosis), the protease inhibitor indinavir (for AIDS), the anti-rejection drug cyclosporine A (for organ transplants), and the anti-arthritis medication penicillamine.

IN ADULTHOOD This, the rarest form of the condition, affects non-pregnant women in their late 20s and early 30s. About half a dozen cases have been reported in medical literature.

who received compliments about her appearance to being a horrible-looking monster? Nobody made comments to my face, but I saw the expression in their eyes. I knew what they were thinking.”

Another source of pain was Shatsi's marriage. Roni, she says, was emotionally absent—to the point where they didn't discuss her condition or anything else. “We lived in the same house but led separate lives,” she says.

For emotional support Shatsi relied on friends, who helped her vacuum and cook because she was too tired to handle all the housework. In frequent phone calls to Egypt, Shatsi told her parents about her escalating size, but

since she wouldn't be photographed, they didn't know how much their only child's appearance had changed.

By her third trimester, Shatsi's breast growth leveled off at an MM cup, but her appetite pushed her weight up to 260 pounds. “I could eat a chicken and still be hungry,” says Shatsi, who gained 110 pounds during pregnancy. (She would later learn that she also suffered from insulin resistance, which fueled her appetite and contributed to her excessive pregnancy-weight gain.)

Throughout her ordeal, Shatsi attended school and kept up a brave front. “I held my feelings inside and tried to look on the bright side: I had friends, and I was doing well in school.” Plus, she was excited about motherhood.

On June 2, 1995, Shatsi gave birth to a seven-pound, six-ounce healthy baby boy. She named him Samir, in honor of her father. “My dad was in New York on business, so he flew to Kansas the next day, and when he saw me he almost had a heart attack,” Shatsi recalls. “I said, ‘I told you I was growing.’ And he said, ‘You didn't grow. You doubled.’”

During the delivery Shatsi dropped 22 pounds in baby weight and fluids, but within 24 hours her breasts became engorged, and a steady stream of milk flowed from each nipple. Nursing wasn't an option: Her breasts were so big that she couldn't position Samir properly, and her over-size nipples prevented him from latching on. Four days later Shatsi began pumping breast milk six times a day, producing 150 ounces—ten times the normal daily amount.

The lactation consultants at Newman Memorial County Hospital in Emporia, where Shatsi gave birth, had never seen a patient like her. But they knew of an Arizona fertility specialist who treated new mothers with lactation disorders and contacted him on Shatsi's behalf. At last she had hope.

INSTANT DIAGNOSIS

By the time Shatsi traveled from Kansas to Arizona to meet H. Randall Craig, medical director of the Fertility Treatment Center in Chandler, AZ, her breasts—though still large enough to rest on her thighs when she was seated—no longer produced enough milk to feed Samir. Craig—who developed an international reputation as a gigantomastia expert in 1988, after an article he wrote about a patient with the



Shatsi hopes to have two more children.

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condition was published in a medical journal—made an instant diagnosis. He told Shatsi that she suffered from the gestational form of the disorder, thought to be triggered by the breast tissue's oversensitivity to hormones—including estrogen and progesterone—that increase during pregnancy. Craig added that while there's no prevention or cure, there is treatment. Shatsi wept tears of joy: “It was wonderful to meet a doctor who knew what was wrong with me.”

Craig prescribed the anti-nausea drug Reglan to regulate Shatsi's lactation and explained that once she weaned Samir from breast milk, he would switch her to Parlodel (a drug that shuts down lactation) to shrink her breasts. He also introduced Shatsi to a designer who measured her for custom-made bras, and to Vicki Pena, a lactation consultant who taught Shatsi how to operate a breast pump more effectively. Pena had heard about gestational gigantomastia but had never met a patient. “When I saw Shatsi, she was so enormous that I was at a loss for words,” Pena recalls.

Shatsi returned to school that summer, shuttling between campus and home several times a day to pump breast milk for bottles; she also pumped in the middle of the night. “Samir wasn't an easy baby—he was colicky,” says Shatsi. Fortunately, she had the help of both her mother (who came from Egypt to stay with her for a few months) and a babysitter. Asked if her condition affected her ability to bond with Samir, Shatsi replies without hesitation, “I always loved him. My illness never affected how I felt about him. But it zapped my energy, so it took me longer to do things.”

By the fall Shatsi had weaned Samir, and her breasts had shrunk to size 38D with the help of medication. Finally she began to reclaim her body.

Craig had warned Shatsi that her gigantomastia would recur in any future pregnancies. So in December 1995, when Shatsi—still married to Roni—learned she was pregnant, she was petrified. “It's not that I didn't want another child,” she explains. “But I thought that what I'd endured in my first pregnancy was the worst thing that could ever happen to a person. I thought I'd die if I ever got pregnant again.” Shatsi says that Roni told her he didn't care whether or not she had an abortion. *(continued on page 151)*

breast nightmare

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A call to Craig helped put her mind at ease. "With monitoring and medication, we can keep the condition under control," he explained. "You won't suffer like before." Shatsi decided to have the baby. And she never had any second thoughts about her decision, not even when the condition returned and her breasts shot up to an NN cup—larger than they had been at the end of her first pregnancy. Craig steadily increased the Parlodel dosage, which quickly reduced the size of her breasts to an FF cup, prevented regrowth, and suppressed her appetite. "It was almost a normal pregnancy," she says.

On September 10, 1996, Shatsi delivered Omar, a healthy eight-pound, six-ounce boy. "When I saw him," says Shatsi, "I said to myself, How could I have thought about ending this?"

A NEW LIFE

When Omar was an infant, the family moved to Louisiana so Roni could pursue a Ph.D. at the University of New Orleans. Shatsi, who also speaks Arabic, French, and German, worked part-time as an interpreter for law firms and hospitals.

During the next two years, Shatsi, down to a DD cup after pregnancy but still weighing 260 pounds, struggled unsuccessfully to slim down. Shatsi's misery was compounded by her marriage; she was so unhappy that her friends and professors urged her to get a divorce.

In the fall of 1997, Shatsi's life took a happy turn when she found a kindred spirit in Youssef Ajjaoui, an acquaintance of her husband. During get-togethers at Shatsi and Roni's home, she and Youssef, a dashing Lebanese man with pale blue eyes, bonded over all they had in common: Both were only children raised in the Middle East; both were depressed about being overweight; both were in troubled relationships. "Youssef's ex-wife and [Roni] were born on the same day in the same year," says Shatsi. "They were both verbally abusive and selfish. We used to joke, 'Why don't we get these two together and see what happens?'"

More hope for a happier life came six months later, in the form of a call from Craig. Since her last visit to his office, two years earlier, medical research had revealed a link between insulin resistance and polycystic ovarian syndrome—a disease that causes irregular menstrual periods and female hormonal imbalance. Shatsi had

PCOS, and Craig suspected that she had an insulin problem, too—which could explain her excess weight. Craig asked Shatsi to have her blood tested.

Sure enough, she tested positive for high insulin resistance. Craig prescribed the antidiabetic medication metformin, which curbs hunger by regulating insulin. Soon Shatsi was able to stick to a diet. After a year or so, by about the fall of 1999, she had shed 100 pounds and treated herself to a new wardrobe that showed off her figure.

By reclaiming her body, Shatsi found the courage to change her life. Last spring, after Shatsi decided that she couldn't stay in an unhappy marriage, she and Roni returned to Egypt to obtain an Islamic divorce, and she sought custody of Samir and Omar.

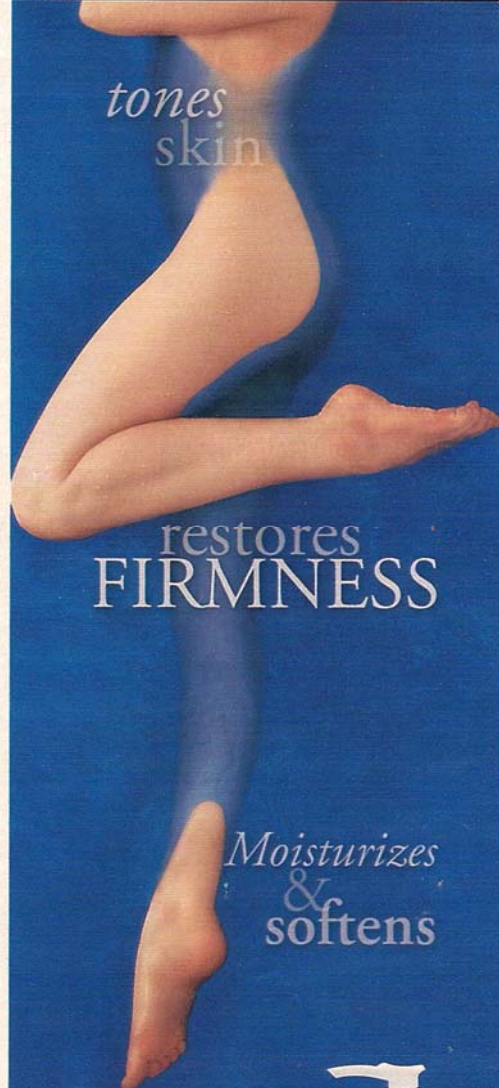
While Shatsi was waiting in Egypt for the divorce to be granted, she and Youssef spoke regularly by phone. Over the years their relationship had evolved from what they call "acquaintances" to "best friends." "We understood each other perfectly," says Shatsi. "He was so easy to talk to. He knew everything about my life—my condition, my children, my problems with my husband." Inspired by Shatsi's example, Youssef, a hotel manager, went on a diet before she left for Egypt, shedding 45 pounds while she was gone. And last September, after Shatsi's divorce was final, Youssef proposed marriage. They wed in November.

Shatsi is philosophical about all that she has endured. "I feel that every bad experience in life either breaks you or makes you a better person," she says. "You may hate what's happening, but you have to figure out how to deal with it. And once you get through it, you emerge more mature and wiser."

These days Shatsi and Youssef are the picture of newlywed bliss as they hold hands and gaze lovingly at each other. Indeed, when Shatsi talks about her new husband and their future, she radiates both joy and relief—the look of a woman who has just received good news after a big scare. They hope to have two children together. And Shatsi isn't afraid of enduring additional bouts of gigantostasia, because she is confident that medication will keep it under control.

Until then Shatsi will be grateful for Samir, Omar, and Youssef. "My life is perfect these days," she says. "I have my health back. I have my body back. What else could I ask for?" □

Additional reporting by Renee Bacher.



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