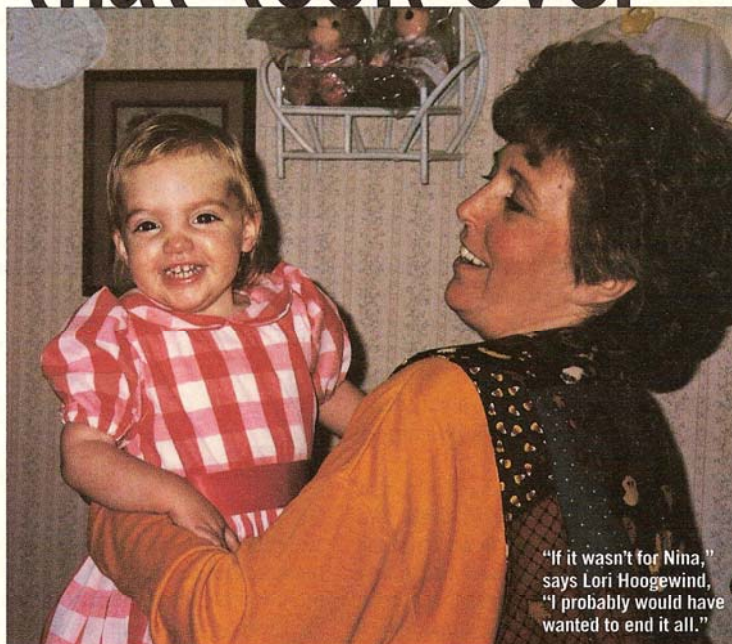


The tumor that took over her life

Doctor after doctor refused to remove Lori Hoogewind's horrifying 200-pound tumor because the surgery could have killed her. But love for her daughter made her risk it all.

BY CYNTHIA HANSON



"If it wasn't for Nina," says Lori Hoogewind, "I probably would have wanted to end it all."

Lori Hoogewind is thankful for simple pleasures: She can shift the gears in her Jeep and lift herself off the sofa without assistance. She can go to the grocery store without attracting rude stares and whispers. She can make it to the mailbox without the aid of a walker. And she can look at herself in the mirror without crying.

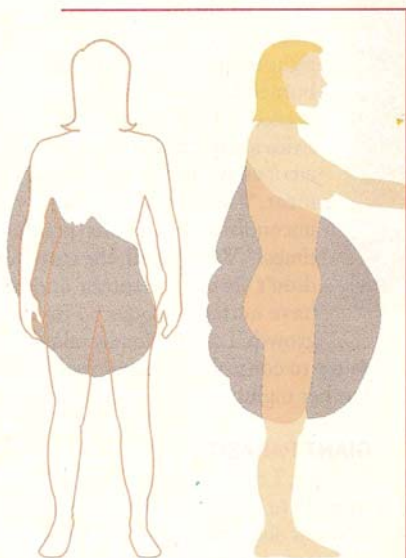
It wasn't all that long ago that Lori, 41, an auto insurance company clerical worker from Wyoming, MI, couldn't do much of anything for herself, her husband, Gary, 43, a Black & Decker repair technician, or their 4-year-old daughter, Nina.

"I missed the little things in life that I had once taken for granted," Lori says today. "But most of all, I missed being a mom. Toward the end, Nina couldn't even sit on my lap, because I would sit down and my lap would be gone."

On a sunny March afternoon, Lori is propped up in bed at the University of Chicago Hospitals, recovering from surgery to replace skin she lost after an 18-hour surgery last December—an operation that was so risky several doctors refused to perform it. For much of 1999, Lori was the prisoner of a fast-growing, blood-sucking tumor that wrapped around her torso like a horseshoe and weighed an incredible 200 pounds—an extremely rare consequence of a disorder called neurofibromatosis (NF).

"You could barely even find Lori within the tumor," recalls Priscilla Short, M.D., a neurogeneticist at the University of Chicago, where the operation to remove the tumor was performed. "It was grotesque, like something out of science fiction."

The tumor—thought to be the largest ever recorded—had been growing slowly for years. When its growth suddenly accelerated, doctors warned her that removing it could cause her to bleed to death. But Lori was dying anyway. The weight of her tumor caused her heart to beat at one-and-a-half times its normal pace, and that was starting to cause heart failure. It leached blood from her brain, making her so disoriented that she'd scold her husband for sending away the firemen she imagined in their home or wake him in the



Lori's tumor (in gray)—thought to be the largest ever recorded—wrapped around her torso like a horseshoe and leached blood from her body.

200-pound tumor

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middle of the night to say he was late for work. And it rotted the skin on her back, making her body reek.

"The life I had really wasn't a life at all," Lori says of her fight for treatment. "If I had taken no for an answer, I would definitely be dead."

TICKING TIME BOMB

For all her suffering, Lori is remarkably upbeat. An outgoing woman with bright blue eyes, a wide smile, and a hearty laugh, she stands five foot six and weighs 130 pounds. To see her slender frame reclining in a hospital bed, it's difficult to picture this woman at a presurgery weight of 310 pounds.

The roots of Lori's medical crisis stretch back four decades. When she was 3 months old, her parents noticed a small lump on the middle of her back, along with a flat, tan mark (known as a café-au-lait spot) on her left thigh, and a dark pigment that extended from her chest to her pelvic region. "We asked the pediatrician about it, but he said we had nothing to worry about," says Lori's mother, Lorraine Huyser, 75.

It wasn't until Lori turned 10 that she was diagnosed with NF, an incurable genetic disorder that affects one out of every 4,000 births. NF causes recurring nonmalignant tumors (called neurofibromas) to form on the nerves of skin and vital organs. It can also cause skeletal abnormalities such as scoliosis. (Café-au-lait spots and other skin discolorations are telltale signs of the disease.) Most sufferers live perfectly normal lives punctuated by surgery to remove their tumors. But those stricken with NF have an increased risk of cancer.

By high school, Lori had had several small benign lumps removed from her right thigh. But her doctor wouldn't touch the small lump that had been growing on her back ever since childhood, fearing that it was connected to her spinal cord and that she would end up paralyzed. In any case, that lump "never stopped me from doing anything," Lori recalls. "I didn't wear a bikini (because of the darker pigmentation on her stomach), but I never had the shape for that anyway."

In fact, she didn't think too much about her medical condition until she

and Gary got married in 1984 and then tried to conceive a child for three years. "I knew that I had a 50 percent chance of passing NF on to a child, so when I didn't get pregnant, I thought it was the Lord's way of telling me that it wasn't supposed to be," she explains.

Still eager to become parents, the Hoogewinds contacted a local adoption agency in 1987 and put their names on the waiting list. Meanwhile, the once-small tumor on her back continued to grow, pushing her weight up to 175 pounds. Several birth mothers contacted

during the procedure. Around the same time, Lori noticed a small, soft bulge on her abdomen. "It didn't hurt," she says. "It looked like I was chubby, so I didn't worry about it."

Word that the Hoogewinds would finally be able to adopt a baby came in the winter of 1996. Around the same time, Lori noticed a new tumor on her right side. Located four inches below her armpit, it was hard and painful, unlike her others. Fearful of a diagnosis that could jeopardize the adoption, she put off seeing a doctor. "We had to send health

"Toward the end, Nina couldn't sit on my lap," says Lori, "because I'd sit and my lap would be gone."

and then rejected Lori and Gary for this reason, she believes. "My weight was included on the application," she says. "If I were a young girl trying to pick a

forms to the adoption agency, and I didn't want them to receive anything that said I had cancer," says Lori, who brought her daughter, Nina, home when she was six weeks old. "A child was what I wanted most in life. And I knew that I would eventually go to the doctor and have it taken care of."

Doctors removed the mass below her armpit in January 1999. It was by then the size of a grapefruit and rock-hard; a biopsy confirmed that it was malignant. Lori received radiation therapy to kill any lingering cancer cells and also to try to shrink a basketball-size tumor which had developed on her right thigh and hip. The radiation burned Lori's skin so badly that it needed to be washed and bandaged twice a day for six months. "It was an open wound. It looked like raw meat," she says. "It was very uncomfortable, and even painful at times." Worst of all, the treatment didn't shrink the tumor and may have actually triggered its rapid growth. Lori had finally taken steps to try to control the disfiguring disease, but her nightmare was just beginning.



Lori, four months after surgery, with Gary and Nina.

picture-perfect family for my baby, I would have done the same thing. It got to a point where we didn't think that we would ever get a baby."

By 1990, when she turned 31, the tumor on her back drooped down over the right cheek of her buttocks. Her doctors at the University of Michigan in Ann Arbor removed ten pounds of that tumor but opted not to take off any more of it because she had lost so much blood

GIANT PARASITE

By May, Lori's pant size had ballooned from 24 to 32. At first she convinced herself that she had simply put on weight. She went on a diet and continued to busy herself with Nina and her work at the insurance company. "We functioned like a normal family," says Lori. (continued)

200-pound tumor

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Whenever she found the time, Lori would indulge her passion for crafts—making quilts (she belonged to a quilting guild) and clothes.

But after a few months of dieting didn't work, she knew that the once-small bulge on her stomach was probably to blame. Concerned about its rapid growth, she went to a genetic oncologist in Ann Arbor. Stumped for an explanation and leery of surgery that could make her bleed to death, the doctor advised her to come in periodically for checkups. "The attitude was 'Let's just wait and see what happens,'" she recalls.

By summer, the stomach tumor was growing at the frightening rate of a pound a day. It was also beginning to wrap itself around Lori's trunk and back—the same area where her skin was darker than on the rest of her body—to connect with her other tumors.

When Lori couldn't squeeze behind the wheel of her Jeep, she removed and reinstalled the driver's seat for more room. When she couldn't lean over to reach the door handle, she used a window scraper to pull it shut. When she couldn't get off

Throughout her ordeal, Lori continued to work. She needed the health insurance for herself and her family (due to enrollment deadlines, she couldn't switch to her husband's plan at the time), and working helped her maintain some normalcy in what had become an increasingly abnormal life. "Lori is a tough customer," says Gary. "She's not one to do the 'poor me' routine."

Still, she was emotionally drained. She loathed strangers' stares and whispers and tried to tolerate their questions. "When I was at the hospital awaiting the hydrobath, I sat in a wheelchair and other patients automatically thought I was pregnant," Lori says. "They'd ask, 'Are you having twins or triplets?' I'd smile and say, 'Triplets.' It was easier than trying to explain."

As Lori's condition continued to deteriorate, Gary took on the household chores, including cooking, laundry, and giving Nina her nightly bath. He also needed to help Lori bathe herself and use the toilet. Sex was out of the question.

"There were times when Gary had to do more than a husband should," says Lori, noting that he never complained about having his world turned upside down. Adds Gary, "If it were me, Lori would have done the same. That's why

now was fed by thumb-size blood vessels, but they ruled out surgery again because of the high risk that Lori would bleed to death on the operating table. "Doctors are not in the business of killing people," explains Madelyn Kahana, M.D., the critical-care anesthesiologist who eventually treated Lori. "The risks were enormous."

Lori felt that her doctors had simply given up. "They lacked the technical expertise to perform the surgery, and nobody wanted to take a chance on me," she says. "They never came out and said I was a hopeless case, but it was implied." A social worker at the NF clinic in Grand Rapids even gave her a book on coming to terms with death. "She urged me to write down things I wanted Nina to know at different times in her life, like on her sixteenth birthday or wedding day," Lori recalls. "But I wouldn't accept the fact that it was the end."

So Lori vowed to get help on her own. First, she called the world-renowned Mayo Clinic but was told the center didn't treat NF. Lori's 32-year-old niece, Michelle Black, called the National Institutes of Health for referrals to NF experts and was given the names of doctors at Johns Hopkins University. They, too, said they couldn't remove the tumor.

Lori then went to a rehabilitation hospital in Grand Rapids to try to get a compression harness to lift up a portion of the tumor which now sagged all the way down to her knees. The tumor was too heavy for the device, but a hospital worker gave her an article about NF by Short—and the hope of help. In

October, Lori met Short at the University of Chicago. In that first meeting, Short said, "You need to see Dr. McKinnon."

MIRACLE SURGERY

A plastic surgeon specializing in craniofacial surgery at the University of Chicago, McKay McKinnon, M.D., has treated NF patients for 20 years. But even he was not prepared for the sight of Lori.

"I've seen a lot of unusual cases, but hers was the most unusual," he says. "The tumor was twice the size of her actual body. She was dying because the tumor was outgrowing its blood supply."

McKinnon isn't sure what triggered the explosive growth of Lori's tumor—it's unclear what prompts tumor growth in any NF patient—although (continued)

Lori felt that her doctors had given up on her: "Nobody wanted to take a chance on me. They never came out and said I was a hopeless case, but it was implied."

the sofa without help, Gary put it on a platform and built a ramp so that she could slither off. When she couldn't squeeze into jeans of any size, she switched to baggy cotton dresses. And when she couldn't fit in the bathtub anymore, she started bathing in a whirlpool at a local hospital.

Even sitting and sleeping became increasingly difficult: Lori sat at a 45-degree angle, placing all of the weight on the left cheek of her buttocks because the tumor was now hanging off her right cheek. At night, she'd fall into bed, roll onto her left side, and ask Gary or her sister, Jan Huyser, to lift the tumor off her leg and lay it on the mattress. "Sometimes, we'd prop it on a pillow," says Huyser, 51, who helped take care of Lori during her illness.

you're married. No matter what, you have to take care of your mate."

Lori says that her crisis actually strengthened her marriage. "It brought us closer emotionally, because it made Gary appreciate all the things that I do to keep our lives and our house running smoothly," she explains.

Still, Lori adds, "In some ways, my illness was even harder on Gary than it was on me. He saw it rob me of my energy and my freedom. He would leave for work wondering whether I would be alive when he came home."

By late summer, with her heart racing and her breathing a labored wheeze, she knew her health was sinking fast. She begged her doctors at the University of Michigan to remove the tumor, which

200-pound tumor

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he thinks that her radiation therapy may have been responsible. And he wasn't surprised that other surgeons had declined to operate on her. "They probably felt that Lori's condition was lethal and that surgery wouldn't save her," he says.

McKinnon believed Lori had a 50-50 chance of surviving the operation. "I was willing to give surgery a try as long as she accepted the risks," he says.

She did. "Either I went for the surgery or I continued on and died," Lori says. "I was thrilled to finally find a doctor who was willing to help me."

McKinnon needed weeks to assemble a team that included a cardiovascular surgeon (in case she needed a bypass during the surgery) and an anesthesiologist, and to choreograph the operation with near-military precision. There were no similar cases in the medical literature to help guide them, and they had various scenarios to consider: What if the tumor was malignant? What if Lori suf-

fered organ failure because of the physical stress of surgery?

As McKinnon developed his strategy, Lori's condition worsened. "If it wasn't for my daughter, I probably would have wanted to end it all," she says. "I had no life anymore; I existed. Once, I said

November, Lori had become so disoriented that after Gary and Jan spent 30 minutes getting her from the sofa to the bathroom, she'd ask them why she was there and what she was supposed to do. Says Jan: "It was like talking to a little kid. Lori was very confused."

When Lori left to have her surgery, she and her husband kissed and were careful not to say good-bye. But, says Gary, "I thought I'd never see her again."

to my mom, 'I just want to die.' She cried and cried. As a parent, you don't want to hear your kid say that."

No longer able to work or walk, she spent her days on her living-room sofa, watching old sitcoms on cable TV, staring out the window, and feeling such despair that the doctor at the NF clinic in Grand Rapids prescribed an antidepressant. The stench from Lori's rotting skin was so intense that Jan bought air freshener by the case. By mid-

When McKinnon telephoned to say that he had scheduled the surgery for January, Lori insisted that she would die by Christmas without it. They decided to move up the date.

In early December, Lori returned to Chicago for pre-operative tests. Kahana, the critical-care anesthesiologist, was shocked when they met for the first time. "The tumor was sapping Lori's nutrition and energy," she says. "Her face was gaunt, her arms were bone thin, and



Now, feel

her breathing rate was quick because her heart had to strain so much. She looked like a cancer patient."

On the morning of December 13, as a medical van pulled into the driveway to transport Lori to Chicago for the surgery, the Hoogewinds were careful not to say good-bye. Instead, they kissed and promised to see each other soon. "In truth, I thought I'd never see her again," admits Gary, who stayed home to take care of Nina during Lori's six-week hospitalization while Lori's sister and parents went to Chicago for the surgery. After Lori left, says Gary, "I went into the house and cried."

The next day, a team of doctors worked around-the-clock to remove Lori's tumor. The 18-hour operation was one of the most technically demanding of their careers and was also something of a work of art: McKinnon's chief challenge was to remove the tumor along the plane of Lori's normal tissue, rather than cut the tumor itself and risk the possibility of uncontrollable bleeding. Meanwhile, Kahana had to keep Lori unconscious while maintaining her blood pressure at a safe level—a task that was made even more difficult because the

wrong drug could send her already failing heart into cardiac arrest.

All told, Lori lost more than 50 pints of blood—equal to more than ten times her entire blood volume. Forty percent of her skin was sliced off with the tumor, giving her the appearance of a burn patient. Miraculously, Lori's heart pumped on its own and all of her organs were undamaged and intact.

A biopsy revealed—surprisingly—that the tumor was benign. Says Kahana: "Most benign tumors don't grow as quickly as Lori's did, so we suspected that it was malignant. It's one of the stunning facts of this case."

A NORMAL LIFE

These days, Lori is happily on the road to recovery. She exercises with a physical therapist to help rebuild the muscles in her arms and legs and increase her range of motion. Lori can stand up almost straight now (until a few months ago, she leaned to the left as she did when she had the tumor and used a cane in public to make her feel more steady on her feet). She receives long-term disability but hopes to return to work when Nina attends school full-time.

Meanwhile, Lori continues to undergo skin grafts (skin has been taken from her legs and back to replace the skin she lost during the surgery). Her medical bills continue to climb past the \$500,000 it cost for the initial surgery and hospitalization; fortunately, insurance will cover all but a few thousand dollars.

Her long-term prognosis is good, and while she may get more small tumors in the future, McKinnon isn't worried that Lori's massive tumor will reappear. "I've removed 20-pound tumors from my other neurofibromatosis patients, and those tumors have not returned," explains McKinnon, who examines Lori every few months. "But if a tumor starts to grow, we should be able to catch it before it becomes life-threatening."

Lori's too happy to live in fear of the future, anyway. Now a size 10, she's thrilled to spend her days caring for Nina, sewing quilts, visiting garage sales, having lunch with friends, getting her hair styled at a salon, doing woodworking projects, and wearing makeup—all the little things she missed during her illness.

"It's such a treat to be able to go wherever I want to go without asking for help," says Lori. "I feel alive again." □

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