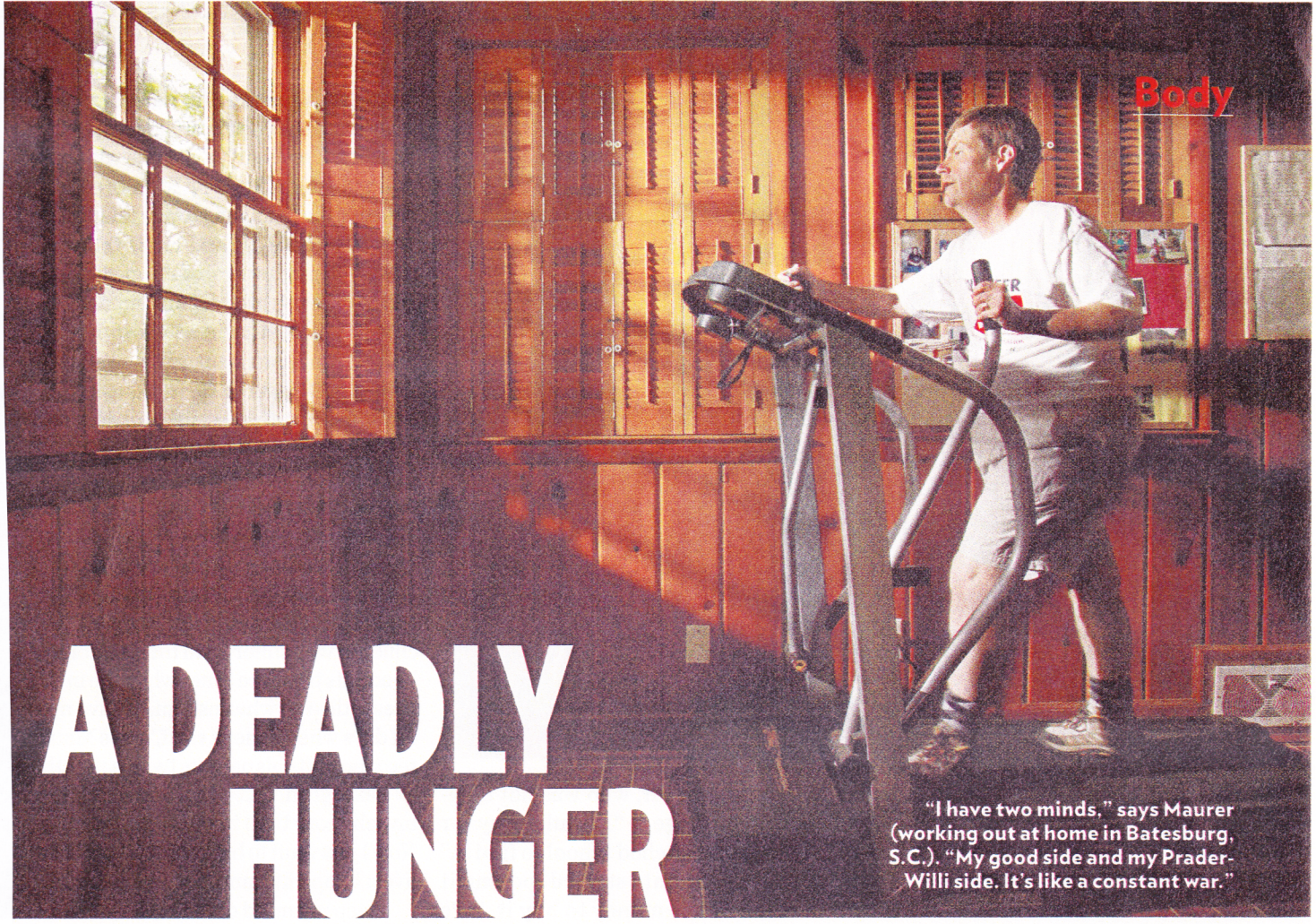
A DEADLY HUNGER



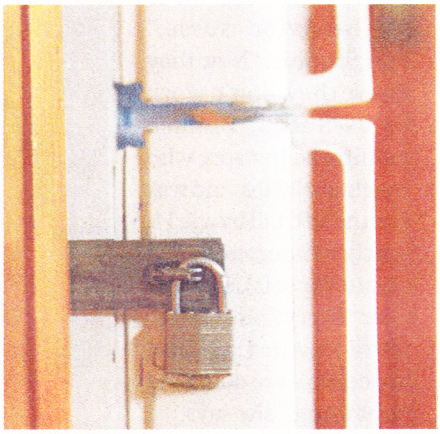
"I have two minds," says Maurer (working out at home in Batesburg, S.C.). "My good side and my Prader-Willi side. It's like a constant war."

More than 5,000 Americans with a rare syndrome simply can't stop eating—even if it kills them

Around the time Andy Maurer turned 3, his parents realized their toddler had a remarkable appetite. Every meal, he ate every morsel and asked for more. Then they found him scrounging in a trash can and sneaking into a neighbor's house to raid the fridge. As he got older, Maurer hoarded food, even raw onions, and once consumed a 1-lb. bag of brown sugar. "I didn't know what my problem was," recalls Maurer. "Anything I could get at, I would eat."

Four decades later, Maurer, now 45, still battles a seemingly insatiable appetite. He's one of 5,000 people in the U.S. known to be affected by Prader-Willi syndrome, a rare genetic defect that causes a ceaseless, uncontrollable hunger. There's no cure, only treatment through constant monitoring and simply keeping food out of reach. "In order for us to stay alive, we have to have the refrigerators and cabinets locked," says Maurer. Says Bronnie, his mother: "He can literally eat himself to death."

Some people have actually done that. According to the Prader-Willi Syndrome Association, at least 11 people died last year in PWS incidents, either from choking or internal complications. "They perforated their stomachs because they just kept eating," says executive director



"In order for us to stay alive, we have to have the refrigerator and cabinets locked"

Maurer in the kitchen at his parents' Lexington, S.C., home

Photographs by ERIC LARSON

"My mama gave up her life to provide me a good life," says Maurer (age 3, and with his mother, Bronnie, right).

> "I would pray for food. I even ditched school to find it" —Andy Maurer

Janalee Heinemann, who estimates the syndrome occurs in about one out of every 15,000 births worldwide. "They don't get the message of fullness or pain."

The condition is not fatal in most cases but can cause morbid obesity and related illnesses like diabetes. Other symptoms include slowed metabolic rate, short stature, behavioral problems, learning disabilities and, as in the case of Maurer, low IQ. It seems unrelated to ethnicity, diet or family health history.

Ironically, Prader-Willis, as they commonly refer to themselves, start life with little interest in food. Bronnie Maurer, then a stay-at-home mom, and her husband, Stewart, a retired hotel manager, forced Andy to eat when he was a newborn, waking him every three hours. Baffled by his behavior, doctors offered numerous possible diagnoses. "First it was cerebral palsy, then it was a rare kidney disease, then a brain hemorrhage. Finally it was an unknown neurological disease," recalls Bronnie. "Then, when he was about 2½, this feeding cycle just reversed." They were thrilled: He finally wanted to eat.

But once he started, he couldn't stop. "I had a craving for food all the time," says Maurer, who was not diagnosed until age 9. "I would pray for food. I even ditched school to find it." After his parents started locking it away, he stole money to buy it. "We slept with our wallets under our pillows," says Bronnie. "If you try to talk to your other friends about it, they just look at you like, 'That couldn't be true.'"

Doctors provided few options for the family. Appetite suppressants he was prescribed "made his behavior worse," says Bronnie. "Now they know they don't work for PWS at all." Bronnie monitored her son, who weighed 229 lbs. and was around 5 ft. tall by age 14, nearly 24 hours a day and created special diets for him. "Everything we did, we did by instinct and hoped we were doing the right thing," she says.

More is known about PWS today, but no prospective drug treatments exist. "The group home environment is the best option for a normal life," says Dr. Tony Goldstone, a postdoctoral fellow in genetics at the University of Florida who has researched Prader-Willi for more than 10 years. Since moving to a residence in 1996, Maurer has thrived. His 1,000-calorie-a-day meals are carefully measured, and he walks on his treadmill almost daily while watching his favorite soap operas. "It is essential to keep off the weight," says the 5'3" Maurer. He works as a shift coordinator at a trash collection site near his Batesburg, S.C., group home and has a girlfriend. "I'd love to do office work, but they will just not deal with our syndrome," says Maurer, who was once fired from a mortgage company for pilfering donuts.

Now an advisory board member for the PWS Association and mentor for children who suffer from the syndrome, he admits there are times when the urge to eat still overwhelms him. "I have my off days when I sneak stuff," says Maurer, who visits his parents twice a month in Lexington, S.C. "But I can control myself more than in my younger days. Now I just want to help people. I want to live a happy life, and . . ."—he pauses—"... keep my mind off of food."

By Ericka Sóuter.
Kristin Harmel in Batesburg

Keeping busy helps Prader-Willis. "I love horses," says Maurer. "There is a weight limit for equestrians."

COURTESY MAURER FAMILY