

The Girl Who Wouldn't Break

Jessica's bones might be fragile
but her spirit was fighting fit—and
her body responded

BY ANITA BARTHOLOMEW



JESSICA BERNSTEIN'S PARENTS LIFTED HER from her wheelchair and hustled her into her mom's deep blue Honda SUV for the trip to the hospital. Distraught, the elfin 15-year-old begged them: "Don't take me. Please, I don't want to go."

She'd had more surgeries than birthdays; spent more time wracked with pain, recovering from fractures and operations, than she'd spent just being a kid. She couldn't do it any more. Yet, even as she pleaded to be left alone, she knew she had no choice.

A few months earlier, in the winter of 2009, Dr. Jenny Frances, her surgeon at the Children's Center at Manhattan's Hospital for Joint Diseases, had given her a reprieve. One of the supporting metal rods inside Jessica's leg bones had shifted position. But when she begged off getting it corrected, Dr. Frances agreed to wait until the girl felt ready.

But now sharp pains in her right leg told her something was very wrong. Treatment could wait no longer.

Jessica had been born with osteogenesis imperfecta (OI), a rare genetic disorder also known as brittle bone disease. So fragile was her skeleton that both her legs had broken and healed again before she was even born. Countless more fractures followed, almost always to her legs.

As a tot, Jessica wanted to do everything her older sister Marisa did. When other kids were toddling, she pulled herself along on her bottom. Fearing the pressure would fracture

her arms, her grandfather built a scooter to place under her belly so she could zip around the house.

In second grade, Jessica was fitted with leg braces that extended from her hips to her ankles. Thrilled to be walking on her own for the first time in her young life, she wore them 24 hours a day. But the following year, as she walked through a doorway at school, Jessica's foot caught on the threshold. That slight misstep—she didn't fall—was enough to break both her legs.

Three surgeries and eighteen months later, something had changed in the spunky little girl. Until then, Jessica had always been determined to push herself beyond expectations. But now, she sat in her wheelchair, reluctant to do the grueling post-surgery physical therapy that could help her get onto her crutches and back to school. She loved that her friends came often to hang out with her, but she envied them, too. They were free

to play outside and do all the things that everyone else could do. She wanted to be just a regular kid, but even more than that, she wanted to be safe from more pain.

By the time she returned to school in the fourth grade, she cautiously got back to using two crutches, but decided not to even try to get around on just one, as she'd done in the past. She didn't want to fall again. As a little girl, she'd braved the frequent blood

Then came the pain in her right leg. Something was seriously wrong.

BACK IN HOSPITAL, the 15-year-old imagined her efforts had been for nothing. From experience, she knew post-surgical recovery would be long—six months or more—and painful.

But she had a pleasant surprise. This current operation would be somewhat simpler than earlier ones,



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tests her condition required. Now she cried and begged the nurses to leave her be. No more surgeries. No more blood tests. No more—period. She'd had enough of it all for a lifetime.

By the time she was fourteen, she'd reached what doctors expected to be close to her full height: just four-foot-two. But without much physical activity, her weight had ballooned. She wanted to wear the sparkly tops and flowery dresses that all her friends wore. It was especially important to look her best now that boys were suddenly on her radar. So, she challenged herself to lose weight and started to exercise more. The excess weight dropped away and she felt better about herself than she had in years.

Dr. Frances explained, as they reviewed her x-rays. Because the bone had broken at the top only, they could use a smaller incision to pull out the old rod and insert a new one, instead of making the usual long incision from the top to the bottom of the leg.

A few days after the operation, Jessica was surprised to find herself able to sit up in a wheelchair. By the end of her nine-day hospital stay, she tentatively hefted herself onto her crutches—an even bigger undertaking—being careful to keep the wounded leg from touching the floor. Thrilled at how much better she felt than she had anticipated, she started getting back some of her old determination.

Early stage physical therapy usually involved very little movement. "But I realized I could do a lot more," says Jessica. Experimenting with new exercises, relying on her own sense of how far her body could go, "I kind of just made it up on my own."

Using her walker for support, she practiced lifting her body up with her arms, and swinging her legs back and forth. Within six weeks, she could

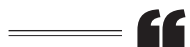
fragile but her body was capable of more. And her spirit was fighting fit as well.

It was getting easier every time to get back to where she was before the operation.

She'd healed well enough to join her friends as they began their freshman year of high school together.

But Jessica had a dream.

Her family lived just four houses



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bend her knee. That, too, was the soonest ever. To ensure she didn't lose muscle in the leg, with Dr Frances's blessing she wrapped a small weight around her ankle and did leg lifts. She taught herself yoga poses. "It helped. I wouldn't get so stiff." She spun on an indoor exercise bike, each day getting stronger and more confident. Dr Frances was stunned, but pleased, that a teenager with OI could become an "exercise fanatic."

Her 15-year-old body cooperated, up to a point. But soon it was clear that her calf wasn't healing properly. Doctors would have to go back in to do another repair. And Jessica would start from the beginning again.

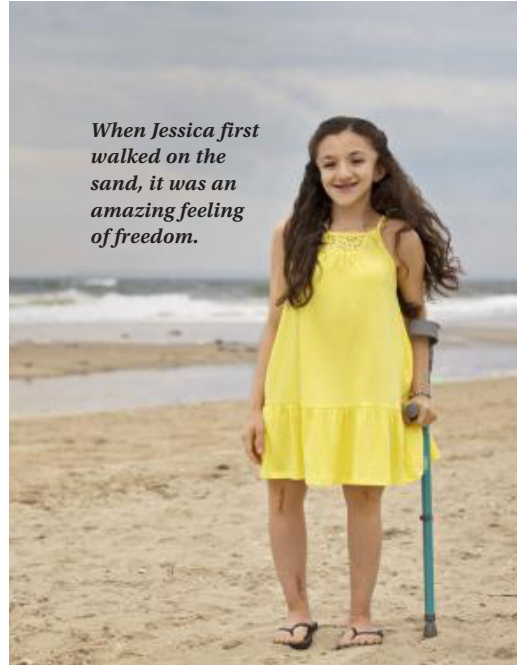
But now, she knew something she hadn't before. Her bones might be

from an idyllic beach on the Rockaway peninsula's Atlantic shore. Jessica longed to stroll the boardwalk like her neighbours but had never been nimble enough on her crutches, or "sticks," as she called them, to navigate the wooden slats. She decided it was time to try. Trekking to the end of the street, she took the ramp up to the wooden walkway, delighting in the scent of the sea and the call of the gulls. The clack of her "sticks" on the boardwalk was the sound of independence.

Life suddenly felt richer, more complete. The boardwalk stroll became part of her daily routine.

Then in late October 2012, Hurricane Sandy struck and the massive waves it caused ripped the boardwalk

When Jessica first walked on the sand, it was an amazing feeling of freedom.



from its moorings. With the boardwalk gone, Jessica couldn't stroll along the beach. Her crutches would be useless on the soft sand. The thought saddened her until she realized this setback didn't have to stop her. She had an idea: What if I could walk without sticks?

With renewed resolve, hanging onto furniture for balance, Jessica practiced getting around the house with a single crutch. It was less difficult than she'd imagined. "So, then, I started to do it quicker." Soon, single stick under her arm, she was walking around the yard. After a few weeks, she was able to walk around the house with no crutch at all, holding onto anything that could stabilize her.

One February afternoon, when the

sun was low in the sky and the winds calm, Jessica dressed in her workout clothes—pink sneakers, gray sweat-shirt, and leggings—and left the house, single crutch under her arm. Neighbors ambled along the beach, some walking their dogs. She headed in their direction, stepping for the first time beyond where the sidewalk ended. Her stick, more impediment than help, sank in the sand. Stopping a moment, she lifted the crutch until it rested across her arms. She took another step. The sand didn't feel the way she'd imagined, but it was wonderful: soft and yielding, yet demanding. She adjusted her stance to find her balance, then coaxed herself along, watching all the other people who took this simple act for granted. To walk freely—they had no idea how amazing it all was.

"I felt so proud," she says. "It was like I'd given birth to the sand."

This past fall, Jessica began classes at a nearby college. She loves to bake and although it means long hours of standing—something she might not have dreamed she could do a few years before—she's decided to follow her heart and study the culinary arts.