



GRATEFUL FOR EVERY HEARTBEAT

*One Woman's Long
And Winding Road
To A Diagnosis*

BY JANET REESE

The first things you notice about Ilene Sloan are her radiant smile, her healthy looks and her positive disposition. You'd never guess she has a serious heart condition known as restrictive cardiomyopathy — an abnormally stiff heart muscle that doesn't relax completely between contractions and can be fatal (see sidebar).

In Ilene's cozy bungalow home in Denver, toy animals belonging to her 13-month-old daughter, Brynn, blanket the living room floor and a tall bouquet of flowers from her husband, Garrett, graces the dining room table.

Today, life is great for Ilene — a stark contrast to the roller-

coaster ride she was on five years ago trying to find a diagnosis for disturbing symptoms she could not ignore.

Let's rewind Ilene's story back to October 2003, when she was 33 years old, single, living in Seattle and working as a federal prosecutor for the United States Attorney's Office. An avid runner, she was training for a marathon.

While shopping and running other errands on a Saturday morning, she passed out in the stairwell of a parking garage. "I woke up to a man shaking me," she recalls. "I pushed him off, grabbed my purse, got in my car and drove off. I thought he was robbing me."

When she glanced in the rearview mirror, Ilene noticed a bruised

bump on her head. "Something was terribly wrong," she says. "I realized that I passed out and had an adrenaline rush from the stranger shaking me awake."

A few days later when Ilene became dizzy and nauseated, had a headache and felt all out of sorts, she rushed over to see her family doctor. "He ran a CT [computerized tomography] scan for my head and a routine EKG [electrocardiogram] for my heart. My heart rhythms showed an unusual and fast wave pattern that was abnormal. The doctor said it was nothing to worry about because 'I was in great shape.'"

Ilene's dad had died of sudden cardiac arrest, and "I thought it's better to be safe than sorry, so I asked for more testing." An echocardiogram ("to see how well my heart pumped") was abnormal, but the doctor again told her not to worry because she was healthy. Ilene was perplexed, because she knew the test results were abnormal — and she also knew they shouldn't be.

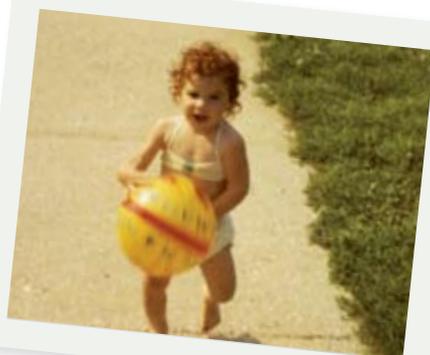
IF AT FIRST ...

Ilene went to see a cardiologist who specialized in diseases involving the heart muscle and was then referred to an electrophysiologist, who mapped out her heart's electrical "wiring." Ilene also took a battery of new tests — including an angiogram to see if there were any problems with the arteries around her heart, and a tilt-table test to evaluate her body's cardiovascular response to a change in position.

But none of the results were adding up to a diagnosis, so an implantable loop recorder was inserted into her chest to record her heart rhythms ("the recorder looked like a traveling toothbrush sticking out of my chest," she says), which revealed ventricular arrhythmias — a potentially fatal heart rhythm disturbance involving the lower right chamber of the heart.

"After eight months of tests, I was thrilled the testing was over," says Ilene. "Then it hit me that I had something serious. The doctors said I had to have a cardiac defibrillator implanted in my chest."

She likened her awareness of the predicament she was in to an



HAVING A BALL

Ilene Sloan as a toddler (top); running a half-marathon (middle); with husband, Garrett, and baby, Brynn (bottom).

out-of-body experience: "I felt really bad for someone else, but that someone was *me*. I thought maybe this was a mistake. I was trying to rationalize it."

Ilene quickly changed her thinking. Instead of wallowing in self-pity, "I could accept the changes as a ... gift. After all, my father died from heart disease when he was only 48. I was 33 and [being] given a second chance."

In July 2004, Ilene had a stopwatch-sized defibrillator implanted just under her left pectoral muscle — where there wouldn't be a noticeable bulge beneath her skin — that would monitor her heart, pace her heartbeat and, when necessary, apply a brief electric shock to prevent a potentially fatal arrhythmia.

GETTING SO MUCH BETTER ALL THE TIME

A few days after the operation, Ilene went to a friend's party where she met Garrett. "A relationship was the furthest thing on my mind," she says. "He left a note on my car with his phone number. I called, and we talked for hours."

Garrett was surprised how someone so young, healthy and beautiful could have a heart condition. "She was probably thinking, 'Was this [heart condition] going to be too much for him to handle?,'" says Garrett, 32. "I enjoyed her so much that she was worth going anywhere for ... even spending nights at the hospital in a folding chair that collapsed once with me in it!"

A month after they met, Garrett spent seven nights with Ilene at the hospital while she had a radiofrequency cardiac ablation (a thin, flexible tube equipped with an energy-emitting probe on the end is guided to the heart so scar tissue causing disordered electrical signals in her heart could be zapped and destroyed).

Within six months of their first date, Garrett proposed, and Ilene accepted without hesitation. Wanting to start a new life together, they moved to Denver in October 2005 after finding a home and jobs — Ilene as an attorney for the United States Department of Agriculture, and Garrett as a financial consultant for Charles Schwab & Co.

Diagnostic tests found **heart function abnormalities**, but Ilene was in great shape so her doctor told her not to worry

In February 2006, they married at a mountain resort in Banff, Canada, a romantic, breathtaking site for their intimate wedding — especially for two people who loved the outdoors as much as they did. And then ... she became pregnant. The couple knew they wanted to have a child, but it would be a high-risk pregnancy for Ilene because blood volume doubles during pregnancy, placing increased demand on the heart, and in Ilene's case, a higher risk of arrhythmias that could affect her baby in the womb.

"The time was right," she says. "[My heart] was stable, and I had more energy." Her ob-gyn, who specialized in high-risk pregnancies, coordinated her care and medications with her doctors in Seattle.

Ilene had no complications, and saw her doctors in Denver twice a week for checkups, and had an ultrasound every two weeks. One

fetal echocardiogram performed at eight months indicated that Brynn's heart was normal and strong.

Today, Ilene takes walks with Brynn and works out with light weights to stay in shape. When she feels up to it, she goes for a light jog from time to time — but marathon running is a thing of the past. Ilene attributes her health to her doctors, medications and lifestyle. Her job is less stressful, since she is able to work from home with the help of a nanny who cares for Brynn during working hours. She is also a board member of the Colorado chapter of the American Heart Association and has given speeches and media interviews about women's heart health as a "Go Red For Women" campaign spokesperson.

"I'm lucky. I could have died in the parking garage where I first passed out. I wake up every day grateful for a heartbeat." ■

ABOUT CARDIOMYOPATHY

Cardiomyopathy is a leading cause of heart failure symptoms (for instance, swelling of the legs and ankles, shortness of breath not caused by physical activity and increased fatigue) and heart transplants — and the most common identifiable cause of sudden death in young athletes. There are three main types:

DILATED (enlarged heart) is the most common form, and can result from a heart attack, a heart valve abnormality or congenital heart disease. In many instances, the exact cause can't be determined;

HYPERTROPHIC (thickened heart muscle) can be inherited, or can occur as a result of chronic high blood pressure that is not well controlled, as well as from various genetic defects in heart muscle proteins associated with certain types of congenital heart disease; and

RESTRICTIVE (stiffening of the heart muscle) is the least common form. As the heart loses its ability to relax between contractions, the ability of the ventricles (lower chambers) of the heart to fill with blood becomes increasingly impaired. Eventually, blood starts to back up into the atria (the upper chambers) and the lungs. Once the lungs are affected, symptoms of heart failure develop.

Increased pressure in the atria can also cause these chambers to enlarge, which can lead to arrhythmias (rapid and erratic heartbeats). Another possible complication is a "heart block" — a slowing or disruption of the electrical signal as it moves through the heart.

Symptoms include fatigue — for instance, decreased exercise capacity or duration — swollen hands and feet (edema), difficulty breathing on exertion or dizziness with

exertion. People whose heart rhythms are abnormal may experience palpitations, lightheadedness or fainting spells.

In many cases, the cause of restrictive cardiomyopathy is unknown, but can occur after high-dose radiation treatment for lymphoma; Chagas disease, a parasitic disease common in Mexico, Central and South America; postsurgical scarring of the heart muscle; excess collagen buildup (fibrosis); or abnormal deposits of amyloid protein in the heart (amyloidosis) that can be caused by chronic inflammatory conditions such as rheumatoid arthritis.

While restrictive cardiomyopathy can develop at any age, the types of disease that result in restrictive heart function most often affect older people and are not gender-specific. Some forms of restrictive cardiomyopathy can also be inherited.

Signs and symptoms of restrictive cardiomyopathy can be subtle in the early stages, and may not be detected with routine testing. In most cases, the diagnosis can be determined using such imaging tools as echocardiography, magnetic resonance imaging (MRI) and/or CT scan, but cardiac catheterization may be necessary — as it was in Ilene's case.

Doctors have a variety of treatment options, depending on what caused the restrictive cardiomyopathy, and the symptoms a patient is experiencing. The goal of treatment is to control symptoms, improve the quality of life and improve survival. For instance, diuretics may be prescribed to alleviate edema and lung congestion to help ease breathing; abnormal heart rhythms can be treated with medication, pacemakers or implantable cardiac defibrillators; and steroids or chemotherapy may be necessary to help keep amyloidosis in check. Should treatment fail to stop the progression of the condition and the heart becomes severely compromised, a heart transplant may be considered.