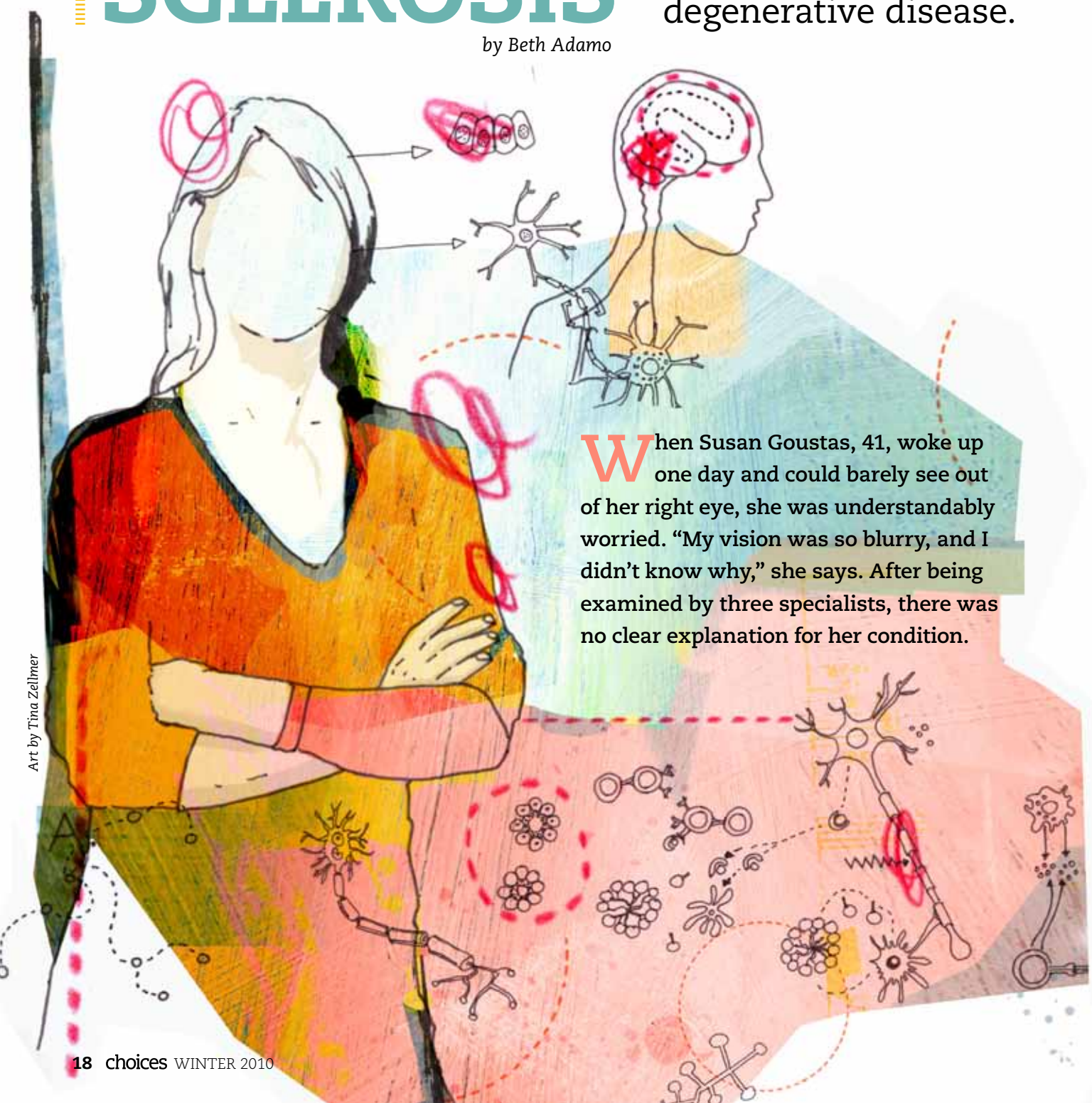
Living with MULTIPLE SCLEROSIS

One woman tells her story of being diagnosed with this degenerative disease.

by Beth Adamo



When Susan Goustas, 41, woke up one day and could barely see out of her right eye, she was understandably worried. "My vision was so blurry, and I didn't know why," she says. After being examined by three specialists, there was no clear explanation for her condition.

Art by Tina Zellmer

Less than two months later, Susan started having severe pain in her neck, and eventually her left arm went completely numb. "I couldn't tie my shoes, or even zip up my pants," she says. "I was in panic mode." After a series of MRI (magnetic resonance imaging) scans of her brain, optic nerve, and neck, Susan received her diagnosis. "I'll never forget the day…'D-day'—diagnosis day—when my doctor told me I have MS [multiple sclerosis]."

What is multiple sclerosis?

MS is a chronic, degenerative, and unpredictable disease of the central nervous system, which is made up of the brain and spinal cord. It can also affect the optic nerves. It can cause people to experience symptoms such as blurred vision, loss of balance, poor coordination, slurred speech, tremors, tingling and numbness, problems with memory and concentration, paralysis, blindness, and more.

With proper treatment, most people with MS can live happy, healthy, and productive lives.

Approximately 400,000 people in the United States have MS, and it's likely there are more cases that are not yet diagnosed or reported. Most people diagnosed with MS are between the ages of 20 and 50. Women are significantly more likely to have MS than men, which has caused researchers to look at the role of hormones in the disease.

There are different forms of MS, and the expected course and treatments are different depending on the type. The most common type at onset is called "relapsing remitting," where an attack occurs, improvement follows, and later another attack occurs. Another type is "primary progressive," which results in a gradual decline and more severe disability.

After hearing her diagnosis, Susan was in shock. "I cried immediately," she says, "but after a while, I realized it wasn't a death sentence, and I decided I had no choice but to make the best of it." Like many people with MS, Susan's symptoms come and go. Her blurred vision lasted for about a month and then cleared up. And she has regained some mobility in her left arm. But it's a slow and unpredictable road.

Causes and symptoms

MS is thought to be an autoimmune disease. This means that the body's own defense system mistakenly attacks the person's healthy tissue. In the case of MS, the tissue being attacked is the myelin sheath, a fatty tissue that surrounds and protects the nerve fibers in the central nervous system. The damaged myelin forms scar tissue, or sclerosis, in multiple places, which gives the disease its name.

When any part of the myelin sheath or nerve fiber is damaged or destroyed, nerve impulses traveling to and from the brain and spinal cord are distorted or interrupted, which can cause any number of the symptoms already mentioned. Because of the unpredictable and patchy nature of the disease, the exact symptoms can vary widely between patients.

The inherent cause of MS—what causes the body's immune system to damage the myelin sheath—is still not known. Studies have shown that it is not contagious and is not directly inherited, although genetic factors may make certain individuals more susceptible to the disease.

Treatment

There's no known cure for MS, but in most cases, there are effective strategies to modify the disease course, treat flare-ups, manage symptoms, improve function and safety, and provide emotional support. Certain "disease-modifying" drugs help to lessen the frequency and severity of MS attacks and reduce the accumulations of lesions (spots of scarring) in the brain and spinal cord, and may slow the progression of disability. In addition to drugs that address the basic disease, there are many therapies for specific MS symptoms.

With proper treatment, most people with MS can live happy, healthy, and productive lives. Since receiving her diagnosis, Susan has made some major changes to live a healthier lifestyle. She exercises regularly and is much more careful about what she eats. "Aside from my symptoms, I've never felt better in my life," she says. "This disease has certainly been a wake-up call."

To learn more about MS, visit nationalmssociety.org.

A Difficult Diagnosis

According to the National Multiple Sclerosis Society, in order to make a diagnosis of MS, the physician must:

- Find evidence of damage in at least two separate areas of the central nervous system, AND
- Find evidence that the damage occurred at least one month apart, AND
- Rule out all other possible diagnoses.

Doctors use the following tools to test for MS:

- Medical history and neurological exam
- MRI (magnetic resonance imaging)
- Visual evoked potential—a test that measures the electrical activity of the brain in response to stimulation of specific sensory nerve pathways of vision
- Cerebrospinal fluid analysis
- Blood tests