

Doc's arthritis struggle shows illness' severity

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This photo provided by David Rickerby, shows Dr. Sue Zieman riding on her scooter, named "Bella", May 31, 2011, in Le Baux, France. Zieman, 47, of Bethesda, Md., is able to enjoy a vacation in France thanks to the scooter that helps her get around despite painfully swollen joints and tendons. She has a mysterious form of inflammatory arthritis, that attacked suddenly two years ago and isn't responding to treatments.(AP Photo/David Rickerby)

(AP) -- Dr. Sue Zieman can almost set her watch by her disease: Twice a day, she gets a fever and the already arthritic joints in her arms and hands, legs and feet abruptly, painfully swell even more. During the evening flare, even the tendons in her feet puff up, rope-like worms just under her skin.

The rest of the day, her joints are so stiff that the once robust Maryland physician frequently uses a scooter to get around. Just [shaking hands](#) hurts the 47-year-old.

[Inflammatory arthritis](#) is disabling Zieman but exactly what kind and what caused it to attack suddenly is a mystery. Nor do her fellow doctors know what treatment to suggest next. She's tried all of today's [arthritis](#) medications with little relief.

Say arthritis, and people tend to shrug it off as a rite of passage of aging. The reality is much more complicated. Arthritis encompasses 100 different conditions and affects about 46 million people in the U.S.

[Osteoarthritis](#) - where cartilage gradually erodes with the wear-and-tear of aging - is by far the most common type.

But inflammatory types - such as [rheumatoid arthritis](#), psoriatic arthritis, [lupus](#) - occur when something makes the immune system run amok and attack the body's own tissues, eating away [cartilage](#) and eventually harming bone. It can strike at far younger ages.

Zieman's saga highlights not just how much doctors still have to learn about arthritis, but how devastating a severe case can be.

"It totally stripped my identity," says Zieman, whose illness cost her career as a [cardiologist](#) and her love of sailing. "I just don't think people realize how debilitated you can be, and young."

She uses humor to help cope, nicknaming her scooter Bella and joking that "I know I'm going to turn into a pumpkin each night" when that 7 p.m. flare sends her to bed.

Infections sometimes trigger inflammatory arthritis, and that's what

probably happened with Zieman. She'd just returned from a business trip to India in December 2008 when she came down with a fever, fatigue and pain in her shoulder and knee. Antibiotics didn't help.

A month later, Zieman became short of breath and both legs swelled. An emergency hospital admission prompted a battery of tests for infections, even super-rare ones she might have encountered abroad. Again, nothing. Maybe it was cancer? Nope.

Then the joints in her wrists and hands began swelling. Soon she couldn't lift a glass. Swelling and pain moved to her ankles and toes.

Her joints had the classic look of rheumatoid arthritis, a disease that affects 1.3 million Americans and that can begin with a low fever and fatigue.

But it wasn't a slam-dunk diagnosis. Blood tests check for specific markers of the disease, such as a substance called rheumatoid factor, and Zieman's results were negative, something that occurs occasionally.

More important, a variety of drugs hit the market in the last 15 years that can rein in the disease and target some of the immune cells doing the damage.

But drug after drug failed, and the illness was spreading to her elbows, knees, hips, even her jaw.

Within a few months, she was on leave from her cardiology job. She couldn't walk up the stairs at home and moved to a one-floor apartment that's walking - or scootering - distance from her new job in aging research at the disability-friendly National Institutes of Health.

She even had episodes of an irregular heartbeat, as inflammation struck

part of the heart.

Then six months ago, she started having those bizarre twice-a-day flare-ups. When she joined some friends for a vacation in France recently, the flares just switched time zones.

That's not typical rheumatoid arthritis, leaving in question Zieman's diagnosis and what to do next.

While Zieman's case is extreme, it's not unusual for inflammatory arthritis to become debilitating so quickly, especially in young or middle-aged women, says Dr. Assil Saleh, a Washington rheumatologist and internist who, along with doctors at Johns Hopkins University and the NIH, treats Zieman.

When an infection is the suspected trigger, patients desperately want to know which bug even though it's usually long gone by the time joints swell, leaving rogue immune cells in its wake.

"Now we're left with a forest fire, and we try to extinguish it," Saleh explains. Most cases of inflammatory arthritis "are not curable but they are treatable in this day and age."

Zieman gets modest relief from very high doses of the steroid prednisone, along with injections of the drug Kineret that targets an inflammation-causing protein named interleukin-1.

She's still hopeful scientists will point her to better treatment as she enters an NIH study. Researchers will videotape her evening flare-ups and try to measure what role that interleukin-1 is playing.

And while she wants to know what's fueling her disease - "I'm as geeky as most cardiologists" - her bigger frustration is how few services help

arthritis patients with daily functioning: "I need to know how to open the fridge."

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