# Diseases Like Mine Are a Growing Hazard

By Donna Jackson Nakazawa
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Some weeks ago, my husband and I treated ourselves to a night at the movies and caught a showing of "The Diving Bell and the Butterfly," the story of a successful French journalist who suffers a massive stroke that changes his life.

As I watched the opening scene and the moment when the main character realizes that he's trapped inside his own body, incapable of moving or communicating with those around him, a shiver of recognition washed over me. Two years ago, I also lay paralyzed in a hospital bed, unable to use my arms or legs, to hug my young son or daughter, or to type a word to meet an impending book deadline. Unlike the movie's protagonist, however, I was immobilized by a type of disorder that afflicts nearly 24 million Americans -- and counting.

Autoimmune diseases -- a group of about 100 conditions in which the body's immune system turns on the body itself -- are reaching epidemic proportions. In the past decade, 15 top medical journals have reported rising rates of lupus, multiple sclerosis, scleroderma, Crohn's disease, Addison's disease and polymyositis in industrialized countries around the world. Over the past 40 years, rates of Type 1 diabetes have increased fivefold; in children 4 and under, it's increasing 6 percent a year.

If I wanted to make a movie about my life, I'd pitch it to Hollywood as "The Diving Bell and the Butterfly" meets "An Inconvenient Truth," the Academy Award-winning Al Gore documentary about global warming. Rising levels of autoimmune disease may well prove to be the next environmental disaster -- only in this case, the changes taking place degree by degree are in the interior landscapes of our bodies.

My paralysis was caused by Guillain-Barr¿ syndrome, an autoimmune disease in which the nerves' myelin sheaths are destroyed by the body's immune system, short-circuiting messages from the brain to the muscles. I've been paralyzed twice in the past seven years. Each time, months of rigorous physical therapy and treatment have enabled me to walk again. But remnants of the disease -- and other autoimmune conditions that have simultaneously ravaged my body -- have left me with a pacemaker, little feeling in my hands and feet, legs that can't ice skate or chase a child, a low white blood cell count and gastrointestinal problems that can land me in the hospital in a blink. Still, I consider myself one of the lucky ones. I know patients who are far less fortunate.

I've spent the past two years interviewing leading experts at top medical institutions nationwide to find out why cases of autoimmune disease are skyrocketing. In recent years, many allergists and immunologists have been attributing the rise to the "hygiene hypothesis" -- the theory that our germ-free homes and childhood vaccinations have eliminated challenges to our immune systems so that they don't learn how to defend us properly when we're young. The scientists I interviewed tended to discard the idea that this alone is responsible. They agreed almost to a person that our day-to-day exposure to environmental toxins -- through the air we breathe and the chemicals we absorb through our skin -- is a major trigger of autoimmune disease. "Exposures from our environment are a significant contributor to today's rising rates," says Douglas Kerr, director of the Johns Hopkins Transverse Myelitis Center and a top clinician at the Johns Hopkins Multiple Sclerosis Center.

In 2003, the Centers for Disease Control and Prevention sampled 2,500 people nationwide looking for the "body burden," or amount of chemicals and pollutants each individual carried. They found traces of all 116 chemicals and pollutants they tested for, including PCBs, insecticides, dioxin, mercury, cadmium and benzene, all highly toxic in higher doses. Then, in 2005, researchers from the Environmental Working Group found something more alarming: a cocktail of 287 pollutants -- pesticides, dioxins, flame retardants -- in the fetal-cord blood of 10 newborn infants from around the country.

Because most toxins are found in only trace amounts, it has been difficult to gauge what effect they might be having on our health. Yet studies of both lab animals and people provide disturbing insights into how even low exposures can cause our immune systems to go haywire. Mice exposed to pesticides at levels four times lower than the level the Environmental Protection Agency sets as acceptable for humans are more susceptible to getting lupus than control mice. Mice that absorb low doses of trichloroethylene -- a chemical used in dry cleaning, household paint thinners, glues and adhesives -- at levels the EPA deems safe and equal to what a factory worker might encounter today, quickly develop autoimmune hepatitis. And low doses of perfluorooctanoic acid, a breakdown chemical of Teflon found in 96 percent of humans tested for it, impair rats' development of a proper immune system.

Evidence from occupational studies is even more worrisome -- because the "guinea pigs" are people. Last year, scientists from the National Institutes of Health and the University of Washington released the findings of a 14-year study of 300,000 death certificates in 26 states: Those who worked with pesticides, textiles, solvents, benzene, asbestos and other compounds were significantly more likely to die from an autoimmune disease than people who didn't. Other recent studies show links between working with solvents, asbestos, PCBs and vinyl chloride and a greater likelihood of developing autoimmune disease.

Proving an absolute link between chemicals and autoimmune disorders in humans won't be easy. Researchers can expose rodents to low doses of chemicals and look for signs of autoimmune disease about six weeks to three months later. But in humans, autoimmune diseases are long, slow-brewing conditions that smolder for a decade or more before symptoms appear. Moreover, Kerr says, it may be that a combination of exposures rather than a single acute dose increases the risk of autoimmune disease.

Meanwhile, we may all be unwitting participants in an uncontrolled experiment as we wait to see whether rising levels of toxins and pollutants in our blood are the cause of climbing rates of autoimmune disease. Our children are the high-stakes pawns in this game: Pound for pound, they eat more food and drink more water than adults, and their immune systems are still developing and vulnerable.

What can we do to lower the stakes for future generations? We could take a page from European environmental policy and its "precautionary principle" of preventing harm before it occurs. Last June, the European Union implemented legislation that requires companies to develop safety data on 30,000 chemicals over the next decade and places responsibility on the chemical industry to demonstrate the safety of its products.

We also need to look beyond the "hygiene hypothesis" as the sole explanation for the autoimmune epidemic and wake up to what immunotoxicologists have been telling us for years: Our immune systems may be less prepared because we're confronting fewer natural pathogens, but we're also encountering an endless barrage of artificial pathogens that are taxing our systems to the maximum.

Finally, we've waited too long for Congress to allocate funding to finding out what toxic exposures can cause our immune systems to turn against us. Though it estimates that 24 million Americans suffer from autoimmunity, the NIH spent only $591.2 million on autoimmune disease research in 2003, the last year for which figures are available, compared with the $5 billion annual budget for cancer, which afflicts 9 million. The NIH budget for cardiovascular disease, affecting 22 million Americans, is four times that of autoimmune diseases.

My health right now is stable. There are challenges, to be sure -- I type these words with braces on my arms. But my legs take me where I need to go. Still, I live in fear of the day when that creeping paralysis could steal my life away again. Only if we take concrete steps now will the movie of my life and that of millions of other Americans have a chance at a happy ending.

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