The Autoimmune Epidemic: Bodies Gone Haywire in a World Out of Balance
By Donna Jackson Nakazawa, Touchstone/Simon & Schuster
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Excerpted from The Autoimmune Epidemic: Bodies Gone Haywire in a World Out of Balance--and the Cutting-Edge Science that Promises Hope (Touchstone/Simon & Schuster).

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Most of us, at some juncture in our lives, have played out in our minds how devastating it would be to have our doctor hand down a cancer diagnosis or to warn us that we are at risk for a heart attack or stroke. Magazine articles, television dramas, and news headlines all bring such images home.

But consider an equally devastating health crisis scenario, one that you rarely hear spoken about openly, one that receives almost no media attention.

Imagine the slow, creeping escalation of seemingly amorphous symptoms: a tingling in the arms and fingers, the sudden appearance of a speckled rash across the face, the strange muscle weakness in the legs when climbing stairs, the fiery joints that emerge out of nowhere -- any and all of which can signal the onset of a wide range of life-altering and often debilitating autoimmune diseases.

Imagine, if you can: the tingling foot and ankle that turns out to be the beginning of the slow paralysis of multiple sclerosis. Four hundred thousand patients. Excruciating joint pain and inflammation, skin rashes, and never-ending flu-like symptoms that lead to the diagnosis of lupus. One and a half million more. Relentless bouts of vertigo -- the hallmark of Ménière's. Seven out of every one thousand Americans. Severe abdominal pain, bleeding rectal fissures, uncontrollable diarrhea, and chronic intestinal inflammation that define Crohn's disease and inflammatory bowel disease. More than 1 million Americans. More than 2 million patients. Dry mouth so persistent eight glasses of water a day won't soothe the parched throat and tongue and the mysterious swallowing difficulties that are the first signs of Sjögren's. Four million Americans.

And, with almost every autoimmune disease, intolerable, life-altering bouts of exhaustion. If fatigue were a sound made manifest by the 23.5 million people with autoimmune disease in America, the roar across this country would be more deafening than that of the return of the seventeen-year locusts.

And yet, despite the prevalence of autoimmune disease, surveys show that more than 90 percent of people cannot summon the name of a single autoimmune disease when asked to name one specifically.

Think of it -- other than walkathons for multiple sclerosis, how many fundraising walks or lapel ribbons have you seen for autoimmune disease in general? Nearly 24 million Americans are suffering from an autoimmune illness, yet nine out of ten
Americans cannot name a single one of these diseases. It boggles the mind.

Each of these nearly 100 autoimmune diseases derails lives. Taken collectively, these diseases, which also include type 1 diabetes, Graves’ disease, vasculitis, myasthenia gravis, connective tissue diseases, autoimmune Addison's disease, vitiligo, rheumatoid arthritis, hemolytic anemia, celiac disease, and scleroderma are now the Number Two cause of chronic illness in America and the third leading cause of Social Security disability behind heart disease and cancer. (Acquired immune deficiency syndrome, or AIDS, by contrast, is not an autoimmune disease; in fact, it is entirely different. In AIDS a virus attacks the immune system and destroys it, whereas in autoimmune disease, the immune system leads the attack, mistaking the body's tissue for an invader and turning on the body itself.)

Autoimmune diseases are the eighth leading cause of death among women, shortening the average patient's lifespan by fifteen years. Not surprisingly, the economic burden is staggering: autoimmune diseases represent a yearly health-care burden of more than $120 billion, compared to the yearly health-care burden of $70 billion for direct medical costs for cancer.

To underscore these numbers, consider: while 2.2 million women are living with breast cancer and 7.2 million women have coronary disease, an estimated 9.8 million women are afflicted with one of the seven more common autoimmune diseases: lupus, scleroderma, rheumatoid arthritis, multiple sclerosis, inflammatory bowel disease, Sjögren's, and type 1 diabetes. All of these can lead to potentially fatal complications.

Or slice these statistics another way: while one in 69 women below the age of fifty will be diagnosed with breast cancer, according to estimates, as many as one in nine women of childbearing years will be diagnosed with an autoimmune illness, which strike three times as many women as men -- and most often strike patients in their prime. According to the National Institutes of Health, autoimmune disease affects far more patients than the 9 million Americans who have cancer and the 16 million with coronary disease.

"The Western Disease": A Rising Epidemic Underrecognized and Underaddressed

Even as autoimmune diseases remain underrecognized and underaddressed, the number of patients afflicted with these illnesses has been steadily growing. Yet few of today's practicing physicians are aware of the escalating tsunami of epidemiological evidence that now concerns top scientists at every major research institute around the world: evidence that autoimmune diseases such as lupus, MS, scleroderma, and many others are on the rise and have been for the past four decades in industrialized countries around the world.

Mayo Clinic researchers report that the incidence of lupus has nearly tripled in the United States over the past four decades. Their findings are all the more alarming when you consider that their research has been conducted among a primarily white population at a time when many researchers believe lupus rates are rising most significantly among African Americans.

Over the past fifty years multiple sclerosis rates have tripled in Finland. Rates have likewise been rising in Scotland, England, the Netherlands, Denmark, and Sweden, where the number of people with MS has been rising at nearly 3 percent a year. Multiple sclerosis rates in Norway have risen 30 percent since 1963, echoing trends in
Germany, Italy, and Greece, where MS rates have doubled over the past thirty to forty years.

Rates of type 1 diabetes are perhaps the most telling. Data over the past forty years show that type 1 diabetes, a disease in which immune cells attack the insulin-producing beta cells in the pancreas, has increased fivefold. The story regarding childhood-onset type 1 diabetes is more disturbing. Studies show that the number of children with type 1 diabetes is skyrocketing, with rates increasing 6 percent a year in children four and under and 4 percent in children aged 10 to 14.

Rates of numerous other autoimmune diseases -- scleroderma, Crohn's disease, autoimmune Addison's disease, and polymyositis -- show the same alarming pattern.

As with all epidemiological research, it can be more art than science to tease out what percentage of these rising rates is the result of more people being diagnosed with a disease because physicians are more aware of it, versus the increase from a genuine rise in the number of people falling ill. Yet the researchers behind these epidemiological studies hold that something more than an improved ability among doctors to diagnose autoimmune diseases is driving these numbers upward.

Norwegian epidemiologists, for instance, argue that rising rates are "due to a real biological change of the disease" rather than being caused solely by better diagnostics and are concerned by the higher occurrence of autoimmunity in urban than in rural areas. Swedish and German researchers concur that enhanced diagnostics alone cannot explain today's significant increases in MS.

Type 1 diabetes researchers insist that today's rapid rise in this disease cannot be explained by either better diagnostics or by more people suddenly becoming genetically susceptible to type 1 diabetes; rather, a change in environmental factors is the "more plausible explanation." At the Mayo Clinic researchers are beginning to ask if rising rates of lupus are the result of an increased exposure to environmental triggers of some unknown origin. Because autoimmune disease is spreading in almost every industrialized nation, scientists the world over have dubbed it "the Western disease."

A Growing Autoimmune Patient Load, An Autoimmune-Disease Crisis in the Making

While epidemiological studies provide a global portrait of an autoimmune-disease crisis in the making, it is through patients' eyes that it takes on more personal meaning. And nowhere is this more evident than at the offices of Dr. Michelle Petri, clinical director of the Johns Hopkins Lupus Center, at the Johns Hopkins Outpatient Center in downtown Baltimore, Maryland. Dr. Petri is a heavy hitter in the field of rheumatology and a nationally known speaker on lupus. Many of the people she treats have waited months for an appointment in order to confirm a diagnosis or gain better treatment for such rheumatic autoimmune diseases as lupus and antiphospholipid syndrome. Some of them are local residents who live merely a few blocks away from her office, while other patients fly thousands of miles to see her.

Over the course of her thirty-year career, Petri has witnessed a dramatic rise in patients with lupus. In the 1960s there were only 150 to 200 lupus patients registered in the Hopkins Rheumatology Clinics. Today, there are 1,700 lupus patients registered from the immediate neighborhood alone. "The population in Baltimore is going down, and yet the number of people coming to our clinic from Baltimore with autoimmune disease is going up," she says.
In an administrative building nearby sits the lupus clinic records room. In the twenty-by-twenty-foot space loom four walls of filing cabinets -- enough to easily fill up the four walls in your local 7-Eleven -- packed with patient files that, twenty years ago, would have fit neatly into a few metal drawers. Although Petri has no way of conducting formal epidemiologic research through her clinic, the continued rise in the percent of patients afflicted in her own small urban area is, she says, a "very disturbing" sign.

Certainly, some of the increase that Petri and other clinicians are seeing in lupus is due to the improved treatment many patients receive through kidney dialysis and transplants, which help them live longer (the longer patients survive, the larger the overall patient number). And the skill with which physicians diagnose lupus has improved somewhat in many large metropolitan hospital centers. However, this increase in lupus "is so enormous," says Petri, part of it can only be explained by an increase in the incidence of lupus itself.

Petri's emphatic tone reveals her concern for her patients' well-being as well as her frustration over how little physicians understand about why so many people's immune systems are attacking their own healthy tissue. The fact that so many front-line practitioners are ill trained in how to diagnose these diseases can result in patients facing costly delays -- both physically and emotionally -- in getting the help they need.

One of these patients was Kathleen Arntsen, a 44-year-old sales professional from Verona, New York. After five years of searching for a diagnosis for what would turn out later to be myasthenia gravis, a disease in which sufferers develop severe muscle fatigue and disabling weakness, Kathleen was told by a doctor she'd been to eight times, "We've given you every test known to man except for an autopsy. Would you like one of those too?" For half a decade, she says, "I was treated like an absolute fruitcake. No one could tell me what was wrong with me, much less treat me."

Arntsen's story is not unusual. The average patient with autoimmune disease sees six doctors before attaining a correct diagnosis. Recent surveys conducted by the American Autoimmune Related Diseases Association reveal that 45 percent of patients with autoimmune diseases have been labeled hypochondriacs in the earliest stages of their illnesses. Some of this, no doubt, has to do with the fact that 75 percent to 80 percent of autoimmune disease sufferers are women, who are more easily dismissed by the medical establishment when hard-to-diagnose symptoms arise. In half of all cases, women with autoimmune disease are told there is nothing wrong with them for an average of five years before receiving diagnosis and treatment. Patients -- most especially women -- are often left feeling both confused and marginalized, or worse, labeled as psychosomatic malingerers.

Arntsen was fortunate to find her way eventually to Johns Hopkins University's neuromuscular clinic and later to Michelle Petri for confirmation, consultation, and validation regarding her polyautoimmune disorders, which include lupus, Sjögrens, Graves' thyroid disease, APS, psoriasis, Raynaud's disease, and myasthenia gravis. Yet despite having an accurate set of diagnoses, Arntsen's autoimmune illnesses have forced her to give up almost everything she once equated with normal life in order to preserve the stamina to get through each day. Once a healthy young woman on a full scholarship to Colgate University, where she was captain of the women's rugby team, Arntsen now has to stop and pick up each knee as she goes up the stairs. "I coexist," she says, "with bone-gnawing pain." For years, her long flame of red hair, which once reached her tailbone, turned scarce and thin, the fallout of her autoimmune thyroiditis,
coupled with drug side effects. In the past decade she has spent almost a year and a half in the hospital during her most severe lupus flares. Although she is carefully monitored, there is little the medical establishment can offer Kathleen for her lupus and myasthenia gravis other than steroids, a healthy diet, and boatloads of rest -- especially since no new U.S. Food and Drug Administration-approved drugs have been developed for lupus in more than forty years.

Kathleen's debility and exhaustion, which have taken a permanent toll on her life and career, will never go away. A top-performing sales rep for an insurance company while in her thirties, Arntsen, who used to run three miles a day, now lives on Social Security disability -- which, she says ruefully, allows time for "my new full-time job -- seeing specialists." She gets going each day by around noon and spends what stamina she has left volunteering at the Lupus Foundation of Mid and Northern New York, which has become her "baby," although it can hardly begin to make up for the fact that "the chance to be a mother has been stolen from me." The best Kathleen and her husband of fifteen years can hope for is that with the careful monitoring of diet, stress, and sleep, she will have more good days than bad.

To look at Kathleen, however, you would never guess what she has been through or what she faces each morning at the start of her day. Like many people who suffer from autoimmune diseases, Kathleen's symptoms remain largely invisible. "Because we go through ups and downs, you might see us on a good day, between severe flares, when we seem to be perfectly fine," she says. "You don't know that we've just spent six weeks in hell." Few can imagine, she adds, that behind her bedroom door even on one of these good days, Kathleen has to take twenty-two medications about an hour before she tries to get up, just so she can handle the pain when her feet hit the floor. "By the time you run into me at the grocery store at two o'clock in the afternoon and say hello to me, I'm ready to nod and say, 'Oh, I'm fine, how are you?'"

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Q. In your book you say that the number of people suffering from autoimmune diseases such as lupus, multiple sclerosis and type 1 diabetes has skyrocketed -- more than doubling in the last three decades. Yet we hear very little about this epidemic. Why?

Nakazawa: Lupus, multiple sclerosis, type 1 diabetes and rheumatoid arthritis are just a few of the more common types of autoimmune disease, but in fact there are nearly a hundred other known autoimmune diseases. One in 12 people -- and one in 9 women -- has an autoimmune disease. That's nearly 24 million Americans. Yet even though autoimmune diseases afflict more than double the number of people who have cancer, and a woman is 8 times more likely to have an autoimmune disease than breast cancer, 90 percent of Americans say they can't name a single autoimmune disease. That's because people just don't know that many painful and life-altering disorders that increasingly afflict so many of their friends and family members today are autoimmune in nature; the body's immune system, which is meant to protect us, is mistakenly attacking the body's own organs and systems.
We also don't hear much about these diseases because the exact process by which our immune system turns from friend to foe was, for many decades, the black box of modern science. Until the late 1970s scientists didn't even agree that the body could turn on itself, much less why. It's only in the last ten years that scientists have been able to show in the lab exactly how the immune system, when it's overwhelmed by foreign invaders such as chemicals and viruses, can go haywire and destroy our own tissue and organs in acts we might think of as "friendly fire." The fact that these diseases have been difficult for the medical community to understand means that even today getting a correct diagnosis can be very difficult. Most people who have an autoimmune disease see six doctors over four years before they get a diagnosis. One patient suffering from severe muscle fatigue and disabling weakness was told by a doctor she'd seen eight times: "We've given you every test known to man except for an autopsy. Would you like one of those too?" It was five years before she got a diagnosis of myasthenia gravis. The medical establishment often lacks a full understanding as to how to diagnose these diseases, dismisses women who complain of symptoms, and often has little to offer in the way of effective treatment. So one reason autoimmune diseases are not on our radar screens is that these diseases were, for many decades, mysterious and not well understood.

Another reason, I suspect, is that on some level we don't want to face the facts. Rates of these diseases have doubled and tripled in industrialized countries around the world over the past three decades. The top scientists I interviewed for my book agree that something in our environment -- something far beyond a better ability to diagnose these diseases -- is causing this health crisis. They are convinced that the cause of this epidemic -- which is world-wide, by the way -- lies primarily in our environment and in all the toxins, pesticides, heavy metals and chemicals that have become a part of our everyday living. We all carry a "body burden" of toxins in our bloodstream, even babies. Several studies show that chemicals commonly used in household cleaners, cosmetics and furniture are present in infant fetal cord blood. This doesn't sound healthy, does it? But even if we agree that this soup of chemicals within us is harmful, what do we do about it? Talking about the autoimmune epidemic is a bit like talking about global warming before the movie An Inconvenient Truth was released. For the longest time, we couldn't see, or didn't want to see, that the smallest rise in temperature would melt the polar ice caps. Likewise, we don't want to know that the ways we're polluting our environment are also harming our bodies and our immune cells. In the international medical world, the scientists who study autoimmune disease call this epidemic "the global warming of women's health." Yet the reality that the environment plays a major role in triggering these diseases hasn't yet trickled down to the rest of the population.

Q. You coin the term "autogen" to describe the agents that trigger autoimmune disease. What are some examples of autogens?

Nakazawa: There are thousands of probable autogens we have not yet studied. Eighty thousand chemicals have been approved for use in our environment. Every year 1700 new chemicals are approved -- that's an average of five a day. Have scientists studied the effects on our bodies of all these chemicals? No. However, those chemicals that have been researched -- in occupational studies and in studies of lab animals -- have been shown to play a role in triggering autoimmune reactions. For example, mice exposed to pesticides -- at levels four-fold lower than the level set as acceptable for humans by the EPA -- are more susceptible to getting lupus than control mice. Mice that absorb low doses of trichloroethylene (TCE) -- a chemical used in industrial degreasers, dry-cleaning, household paint thinners, glues and adhesives -- at
levels deemed safe by the EPA, and equal to what a factory worker today might encounter, quickly develop autoimmune hepatitis. And low doses of perfluorooctanoic acid, a breakdown chemical of Teflon that can be found in 96 percent of humans tested for it, impair the development of a proper immune system in rats.

We know from occupational studies in humans that these chemicals impair our immune systems in dangerous ways. In 2007, scientists from the National Institutes of Health announced -- after studying 300,000 death certificates in 26 states over a 14-year period -- that those who worked with pesticides, textiles, hand painting, solvents (such as TCE), benzene, asbestos, and other compounds were significantly more likely to die from an autoimmune disease than people who were not exposed. Other recent studies show links between working with solvents, silica dust, asbestos, PCBs and vinyl chloride and a greater likelihood of developing autoimmune disease.

Q. But not everyone who is exposed to these autogens comes down with a disease. So, why do some people get an autoimmune disease and not others?

Nakazawa: That's because of a phenomenon I call the "barrel effect." Each person, with his or her unique genetic composition, is exposed to a myriad combination and level of autogens depending on what they encounter in their day-to-day lives through the air they breathe and what they come into contact with through their skin. This toxic stew consists not only of chemicals and heavy metals, but additives in our highly processed diet and viruses and bacterial agents to which we're exposed -- all of which combine to impact our immune system. Chronic stress, which releases cortisol into our body, also plays a role in triggering these diseases as do women's reproductive hormones -- which is why women are three times more likely than men to come down with an autoimmune disease. As long as your barrel is less than full, however, your immune system is still able to deal with what it confronts every day. But once the immune system becomes overburdened it can begin to send misread signals, causing the immune system to make costly mistakes and attack the body itself. Unfortunately in modern life we've created a perfect storm of factors -- a plethora of chemicals, heavy metals, processed food additives, viral hits and stressors -- for today's autoimmune epidemic to take hold. So much of what we encounter in twenty-first century life is causing our barrel to fill to the brim -- and spill over. At that point, disease strikes.

Q. Is it only people with a genetic predisposition who are vulnerable to this "barrel effect"?

Nakazawa: No. Researchers have found that anyone can be susceptible. Whether or not you get an autoimmune disease depends on how many of these triggers you've been exposed to over your lifetime -- or how full your barrel is. People with a genetic predisposition -for example, if you have a close relative who has an autoimmune disease, you may be genetically inclined that way -- may be more vulnerable, but anyone whose immune system is overtaxed or over-stimulated can get sick.

Q. You talk about "clusters" of autoimmune diseases in your book. For example, in Buffalo, NY, in a small neighborhood surrounding known toxic waste sites, an unusually high number of people have developed lupus. And yet, the U.S. Department of Environmental Conservation is doubtful that there's a link. Why is that?

Nakazawa: Clusters are hugely controversial in part because our scientific criteria for proving that exposure A caused disease B in a community are extremely difficult to
meet. Autoimmune diseases take years to appear after exposure, and communities are often constantly changing. People move, or die, or their disease is never properly diagnosed. How can we prove, with all these variables, that a toxic exposure in an area caused a group of people to fall ill with a specific set of diseases? Moreover, so much toxic waste exists everywhere, how can we definitively compare what autoimmune disease rates might be in a non-chemically laden area with those in a highly contaminated area when such clear-cut lines rarely exist in the cities and suburbs where we live? So it's very difficult.

Nevertheless, autoimmune clusters have been shown to exist near toxic waste sites in Buffalo, New York; El Paso, Texas; and Morrison, Illinois and its environs. Many more are being investigated, including in Anniston, Alabama, where investigators funded by the Agency for Toxic Substances and Disease Registry are conducting studies to determine whether high rates of autoimmune disease in the area are linked to an industrial manufacturing site where most of the PCBs in the United States were once manufactured and dumped. From Anniston to Buffalo we live in an increasingly complex sea of autogenic agents.

Still, we say we can't "prove" that chemicals are impairing the human immune system. Meanwhile, European environmental policy uses the precautionary principle -- an approach to public health that underscores preventing harm to human health before it happens. In June 2007, the European Union implemented legislation known as REACH (the Registration, Evaluation, Authorization and Restriction of Chemical Substances), which 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 their products. America lags far behind, without any precautionary guidelines regarding chemical use.

Obviously, political and economic considerations come into play here. There are over 1200 "superfund" sites around the U.S. - areas where deadly toxins are known to be seeping into the environment -- and these have yet to be cleaned up. At about 10 percent of these sites, people are freely entering the area and being exposed directly to the hazardous waste. Unfortunately, the Environmental Protection Agency does not release information about how much it plans to spend to remediate these sites, when the area will be cleaned up or how long it will take.

Q. You were twice paralyzed with the autoimmune disease Guillan Barre Syndrome during the writing of this book. How did you recover?

Nakazawa: Most patients with an autoimmune disease go through terribly difficult times -- or flare-ups -- which can be quite serious. Getting through a downturn involves a combination of factors. If you know what can contribute to disease it's easier to know how you can help yourself. Months of grueling physical therapy, coupled with IVIG treatments, helped me recover each time I was paralyzed. I also had to be vigilant about what goes into my body and avoid coming into contact with things that might overstimulate my immune system. Dietary factors, use of household cleaners, emotional stress -- these all have to be watched and managed. Also, we do a lot of hand washing in my home, especially when there are colds and flu going around, to minimize any viral hits to my immune system. Studies show that patients with an autoimmune disease also do better if they build a wellness plan that involves reducing stress hormones through a daily habit of meditation and whatever form of exercise they can tolerate. Studies show that autoimmune patients also do much better if they follow "the autoimmune diet," which means consuming foods that are anti-inflammatory. For example, most autoimmune specialists agree that patients
should avoid wheat and gluten products and highly processed foods, which can be inflammatory or provoke the immune system to overreact. So one needs to work with a doctor who is open to treating you not just with drugs but also with dietary changes, including making sure you're receiving adequate amounts of the main supplements that have been shown in clinical studies to help autoimmune disease patients, such as omega fatty acids, Vitamin D, antioxidants, probiotics, and glucosamine.