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Lupus on Steroids

> "For a long time he had been white smoke. He did not realize that until he left the hospital, because the white smoke had no consciousness of itself."
> -Leslie Marmon Silko, *Ceremony*

In January 1967, Sandra Frosaker Riley, 32 years old, surprised her husband by telling him that, despite being on the pill, she was pregnant. Subsequently, she was plagued by the average and uncomfortable symptoms of pregnancy; morning sickness, fatigue, and bloating, but other, not-so-average symptoms surfaced as well. Itchy and inflamed rashes appeared on her face and ears. Her joints began to swell, becoming arthritic.

Then, in August 1967, Sandra gave birth to me, a healthy baby boy. As the normal pregnancy symptoms faded, other conditions worsened and new symptoms developed. Her doctors were confused. Her blood tests were irregular, and no diagnosis seemed to account for all of her physical problems. My father, Wallace Riley, grew increasingly impatient with her care providers, because Sandra was getting worse and the doctor's couldn’t provide any relief. Wallace placed me into the care of family friends, while he took Sandra across the country to see specialists they hoped could give them answers. Countless tests were performed, and a host of specialists were consulted, but there were no concrete answers. It wasn’t until 1969 that she was diagnosed with systemic lupus erythematosus (SLE). Two years later, Sandra sustained major kidney damage, and in 1971, she died from kidney failure.

I was four years old, and healthy. Since she had been absent from me during her remaining years on earth, I have no memory of her. I was a fairly healthy child, but was thin and underweight, for my age. As I grew, my chest developed abnormally, resulting in a condition known as pectus excavatum, which is caused by a negative pressure in the anterior mediastinum, which pulls in the sternum, creating an indentation in the center of the chest. I referred to it as “my hole.” My doctors felt that the deformity might impede the development of my heart, so I underwent an operation to correct the abnormality when I was eight.

Throughout my 20s, I made my living working in the restaurant business; starting in the kitchen, then in the front of the house, and eventually as a sommelier. Working the floor of a restaurant is somewhat physically demanding and requires a certain amount of stamina. One day, on my way home, a driver ran a red light and broad-sided my car, totaling it. Luckily, I had *not* been wearing a seat-belt, so I was thrown into the passengers’ seat, thus avoiding being crushed by my driver side door. I awoke in the hospital with injuries that resembled no-more than a serious bar brawl. I was bruised and beaten, but relatively unscathed.

As the bumps and bruises healed, I went back to work, but I started to develop health problems that seemed independent of the car accident. It became increasingly harder to open bottles of wine, because the pain in my hands was increasing. Working a restaurant shift took a tremendous amount out of me. I was exhausted. Rashes developed on my face. My ears itched, unbearably. I couldn’t shake the fatigue. Eventually, I had to take a hiatus to get the rest I thought I needed. My symptoms worsened. To get from the bed to the bathroom took an excruciating effort. All of these ailments crept up on me slowly, fogging my senses. At one point I couldn’t remember what it was like to feel normal, and I was unable to go outside alone.

Eventually, a close friend intervened, driving me to San Francisco General Hospital where I was admitted immediately. The ER team administered morphine, which helped with pain, but decreased my mental acuity further. Dozens of tests later, with my veins having donated tremendous amounts of blood, all in the pursuit of medical clarity, my physicians simply scratched their heads. There's nothing more frustrating than doctor after doctor saying that I could have this or that disease, in such a technical way that I had no idea what they were saying. It took several weeks, and some creative medical thinking, but I was finally diagnosed with systemic lupus erythematosus. It would have happened earlier if I had known my family's medical history, but my father had been vague when speaking about Sandra. Also, the diagnosis was likely hindered because I'm a white male; that makes me an unlikely candidate for lupus. That was in 1995.

It's not surprising it took time to determine my condition. Diagnosing SLE is a challenging process. There is no one "lupus test," and lab tests alone cannot confirm a diagnosis. Current symptoms, medical history, and the patent's family's medical history must be taken into consideration. Many of the symptoms of lupus can be attributed to other conditions, and they appear sporadically, at different times (Lupus Foundation of America). Consequently, misdiagnoses are common.

When lupus is suspected, blood work is performed to try and confirm the diagnosis, but some results are misleading, so the blood tests must be considered as a whole. No one factor can confirm, or deny, the diagnosis. Initially, a complete blood count, urinalysis, erythrocyte sedimentation rate, an ANA (anti-nuclear antibody), and a biochemical profile are performed. The ANA test, if positive, strongly suggests a diagnosis of lupus; however it is also associated with rheumatoid arthritis, and other conditions. The presence of antinuclear antibodies is prevalent among lupus sufferers. If anti-double stranded DNA antibodies and hypocomplementemia, a diminution of complement levels in the blood are detected, it also strongly suggests a diagnosis of SLE. If antibodies to Sm target Sm, proteins in the cell nucleus are found, it almost always means that the patient has lupus though only 30 to 40 percent of lupus sufferers test for them. Glomerulonephritis, also known as glomerular nephritis, can be detected in lupus patients that have renal symptoms (Belmont). These are just some of the factors that must be considered during a lupus diagnosis.

Systemic Lupus Erythematosus (SLE) is an auto-immune disease. In some ways, it's like the reverse of HIV or AIDS. Instead of your immune system breaking down, it mistakenly attacks healthy tissues like your skin, heart, lungs, kidneys, and other vital organs. There are other forms of Lupus, but this paper's focus is on SLE. No news treatments have been release in over 50 years for this disease that more than 1.5 million Americans have (Lupus Foundation of America). Symptoms of Lupus include:

- Achy joints
- Swollen and painful joints
- Unexplained fever of over 100 degrees F
- Prolonged or extreme fatigue
- Skin rashes
- Unusual hair loss
- Mouth or nose ulcers
- Butterfly shaped rash across the cheeks and bridge of the nose
- Chest pain or shortness of breath
- Sensitivity to sunlight
- Swollen ankles
- Fingers that turn white and/or blue in the cold
- Seizures

I suffer from nearly all of them as my Lupus is more severe than most. Lupus is a protean disease; people react differently to Lupus and no two cases are exactly the same (Lupus Research Institute).

Systemic lupus erythematosus (SLE) occurs predominantly in women (nine out of ten cases, overall). The actual cause of the disease is not known, but it is generally accepted that genetics and hormones are major contributory factors.

What's interesting about the condition is that an event usually occurs, causing the subject to become *symptomatic* (Lupus Foundation of America). I suspect there are scores of people who have lupus, and will never show any symptoms. But for those that do show symptoms, something first activates the disease before its symptoms become chronic. Women generally become symptomatic after puberty, or after they've become pregnant, as was the case with my mother. But I postulate that because men don't normally become symptomatic after puberty, lupus symptoms are provoked by a trauma, such as a car accident, and, henceforth, don't actually become aware of their underlying condition nearly as often as women. Again, it's no surprise that it took some time to diagnose me.

When I was been released from the hospital, I hadn't worked in months. Having been bed ridden, I had exhausted my savings. My doctors, upon releasing me, gave me a prescription with multiple refills for prednisone (a corticosteroid) at 60mg per day. They never mentioned the side effects of prednisone, and I naturally assumed it was the appropriate medication for this disease. Having little money, and no health insurance, I was forced to go to the free clinic for medication. They were able to dispense and renew my prescription for prednisone at its original levels, and I became functional, to a certain degree.

Because of personal circumstances, I returned to my home town of New York, N.Y. Not knowing any free clinics there, I took my prescriptions to the pharmacy and paid for them out-of-pocket. Luckily, prednisone is relatively inexpensive, and I was able to afford the medication after landing another job in the restaurant industry. Unfortunately, I still had no access to health insurance, which proved to be a problem when it came to refills for the corticosteroid that was unknowingly destroying my body.

According to Dr. Mark Gourley, "the use of corticosteroids, most commonly prednisone, remains the mainstay of therapy for lupus." He explains, "the patient is usually started on oral daily prednisone at a dose of 40-60mg/day" (Gourley, 283).

I had been working at an establishment that promised health insurance. Debilitating symptoms had developed again, and just as before, I took a leave of absence from work in the hopes of waiting things out, hoping for the insurance to kick in. My mental faculties slowly faded. I lost contact with everyone I knew. But, my suspicious father found me where I had been staying, and luckily, I had forgotten to lock the door. He found me delirious, and unable to walk. He called one of my friends, and together they dragged me into Beth Israel Hospital's emergency room. The doctor who treated me said I had a few days, if not hours, to live. I was treated and released, and this time other medications were prescribed to supplement the prednisone dose of 60mg/day.

Never was I told about the side effects of the medications I was taking. Neither Beth Israel, nor the free clinic, nor San Francisco General ever advised me of the possible ramifications of the prescription I was ingesting, nor did they suggest a program of lessening their use. It would be another year before I was able to obtain medical insurance, and start seeing a rheumatologist regularly.

People diagnosed with systemic lupus erythematosus, especially at a young age, that have been treated with high doses of corticosteroids for an extended period once the disease is detected, suffer needlessly from extreme complications.

When starting steroids, the initial side effects can include dramatic mood swings, acne, increased appetite and weight gain, and water and salt retention, which result in bloating. Over time, side effects include osteoporosis, avascular necrosis of bone and joints, diabetes, fat deposits, cataracts, ulcers, muscle weakness, high blood pressure, oral candidiasis (thrush), hyperglycemia, slowed healing of wounds, and increased risk of infection. The increased risk of infection can be extremely dangerous as most deaths associated with lupus stem from some sort of infection (Lupus site (SLE) - information on systemic lupus).

No other treatment for lupus has side effects as devastating as corticosteroids. Corticosteroids, or glucocorticoids, are synthetic and mimic the body's naturally occurring hormones, more specifically cortisol, produced in the adrenal cortex or glands. In the 1940's' these chemicals were thought to be the cure for arthritis, until their debilitating side effects were uncovered. Other Corticosteroid drugs include prednisone, betamethasone, budesonide, cortisone, dexamethasone, hydrocortisone, and methylprednisolone. Cortisol is naturally produced by the body, in relatively large amounts, during stressful situations, and is sometimes referred to as the “stress hormone.” During these episodes, the body can react with a quick burst of energy, lower sensitivity to pain, heightened memory functions, or short-term, increased immunity, which helps us cope with whatever stress the body is enduring. Cortisol, in normal amounts, helps control the salt and water balance in the body, regulates some metabolic actions, helps regulate blood pressure, and is the most effective anti-inflammatory hormone. Corticosteroids block the production of prostaglandins, and other substances that affect allergies and inflammation. They also inhibit the immune systems’ production of white blood cells, reducing the body’s ability to fight infection (Eustice).

Corticosteroids are used to treat a wide variety of diseases and symptoms. When used to treat lupus, they control inflammation and weaken the immune system, so its ability to attack healthy systems is hampered. Corticosteroids are extremely effective in reducing the swelling and pain in joints throughout the body (Eustice). They can also be used to control lupus “flares,” which occur when symptoms of the disease attack the patient *en masse*. Flares can be severe, and in those instances, relatively massive doses may be administered. This can be extremely dangerous, as the body doesn’t tolerate spikes or sudden drops of steroids well. Eliminating or reducing steroid intake should be done as gradually as possible to avoid a condition known as “adrenal crisis,” which can be life threatening.

"Pain -- has an Element of Blank –
It cannot recollect
When it begun -- or if there were
A time when it was not –

It has no Future -- but itself --
Its Infinite contain
Its Past -- enlightened to perceive
New Periods -- of Pain."

-Emily Dickinson, *The Mystery of Pain*

Because osteoporosis can ensue with steroid use, my rheumatologist, Paula Rackoff, M.D., of Beth Israel Medical Center, schedules a bone density scan at least once a year. Early on, the scans showed considerable bone loss for a person of my age, so she prescribed calcium supplements, moderate exercise, and a diet that included more fruits and vegetables. Although I had adjusted my behavior appropriately, my scans still showed problems, so she prescribed FOSAMAX®, which helps reverse bone loss. The drug proved successful, and once satisfied with its results, she discontinued the prescription.

About ten years ago, I went to Dr. Rackoff's office to get my routine bone density test results. She came into the examination room looking more concerned than usual, so I expected a problem. I expected it to be minor. She explained that it wasn't my bones that were the problem, it was my hips. I had been experiencing hip pain that had been slowly increasing, but I didn't consider it serious. She told me I had developed avascular necrosis in both of my hips, and that they needed to be replaced.

Replaced?

I was shocked. I had no idea that this was even a possibility. My mind raced, considering the time the process would take, the pain, the medical insurance, the recovery. After the initial shock, the left side of my brain took over and I accepted that this situation was beyond my control, and a necessity. I pragmatically said to myself, “Let’s get it done. Let's get it over with.” What I didn’t know was that this wasn’t going to be my last time being shocked in a doctor’s office. There was more to come.

When a patient is relatively young, orthopedic surgeons won’t permit you to replace two hips at once, as a bilateral replacement requires a stay at some sort of recovery facility. My left hip’s necrosis was more advanced, and was the first replaced. While recovering, all I could think about was that I was going to have to go through this all over again. The recovery was painful, but relatively quick. Once my left hip recovered however, it felt wonderful. I hadn’t realized how much it had hurt before the replacement. Pain is a strange thing. When it comes on slowly, it sneaks up on you. It’s hard to remember when it wasn’t there. Once removed, even though you remember the pain, it becomes distant. My second replacement went more smoothly than the first.

My hip replacements

Pain is a strange thing. When it comes on slowly, it sneaks up on you. It’s hard to remember when it wasn’t there. Once removed, even though you remember the pain, it becomes distant. My second replacement went more smoothly than the first.

Several years ago, I started having trouble urinating. Sometimes gas and fecal matter would come out, in addition to urine. After several tests, my doctors told me I had developed a fistula between my intestine and bladder. A fistula is an abnormal connection, or passageway between two epithelium-lined organs. I had developed diverticulitis, a digestive condition where infected pouches develop in the large intestine. One of the infected pockets had burst and created a pathway to the bladder. To correct the problem, I underwent surgery with both an intestinal and urological surgeon. The procedure took more than six hours. I awoke with an ostomy bag. The doctors had given me a colostomy, where the large intestine is tied off and allowed to heal, while solid waste is passed through an opening in the stomach. For seven months I had to maintain the colostomy and its bag, which proved difficult, messy, and embarrassing. Once my surgeons were satisfied I had healed sufficiently, I underwent surgery again to reverse the colostomy. Because my immune system is hindered, through the continued use of corticosteroids, I took great care to treat the wound in an environment as sterile as possible to prevent infection. Luckily, my wound healed without incident. My reminder today is a large, circular, indented wound in my stomach.

Following the colostomy-reversal, my stomach became distended, and to this day my doctors can not explain why. About the time my stomach wound finished healing, pain returned in my hips. I went to my orthopedic surgeon to investigate. A full workup was performed. My hips appeared fine. The replacements looked as good as the day they were installed, and I was told they should be trouble-free for the next ten to twenty years. The pain persisted, however, and I visited one specialist after another. CT scans and MRIs were performed, and months went by while everyone scratched their heads. Then abscesses appeared on my left hip-replacement scar and my mid-right thigh. They increased in size slowly, and eventually burst. Fluid drained constantly from two new open wounds. Obviously, I had an infection. Doctors gave me conflicting theories, while the pain in my hips became so severe that I needed a cane to ambulate. A culture was taken from inside my hips, which proved to be a staph infection in at least one side. My orthopedic surgeon disagreed, however, based on the MRI results and the fact that the infection on my right leg was too low on my thigh.

Should the infection have been in my replacements it would require removing them, inserting blocks into my hip cavities, putting me on an extreme antibiotic regimen for six weeks, and then re-replacing the equipment. In the meantime, it was becoming harder to control the fluid being excreted, and it was decided to remove the surrounding infected tissue using debridement and curettage. We hoped that if the suspect tissue in the region was removed, the problem would be solved. The procedure was performed by a plastic surgeon, who was confident the affected regions were cleared. A pick line was also installed in my arm to administer intravenous antibiotics twice a day during my recovery, in an attempt to combat whatever infection remained. I started the tedious wound care process over again, this time for my hip and thigh.

My right thigh

My left hip

All of these conditions were not brought about by lupus, but by the use of corticosteroids. Prednisone, while having saved my life, has decimated my body. Some patients, like me, will have to take prednisone for the rest of their lives. There are many ways to minimize the amount of steroids any given patient must take, however, and they should be explored vigorously by the lupus sufferer and the caregiver.

> "You know what the Army doctor said: 'No Indian medicine.' Old Ku'oosh will
> bring his bag of weeds and dust. The doctor won't like it."
> -Leslie Marmon Silko, *Ceremony*

There are a variety of alternative therapies used to treat the fatigue, inflammation, skin rashes, and other problems associated with lupus. Sometimes these therapies even claim to cure lupus. For instance, Dr. John H. McDougall, of the McDougall Heath and Medical Center in Santa Rosa, Calif., claims on his web site to have cured lupus for one patient <http://www.drmcdougall.com>. Another claimant, Cheryl Dowery, who suffers from SLE, self-published an e-book called "Cure Your Lupus Naturally," which alleges that for $29.95, lupus and its symptoms can be a thing of the past <http://www.curelupusnaturally.com>. Yet, despite what some authors and doctors claim, there is no proven cure for lupus. Many treatments and non-traditional remedies may provide real relief for lupus sufferers, however.

Fatigue can be a severe problem for lupus patients. Sometimes borderline narcolepsy can ensue. Often, I will be at work, in front of my computer, or in a meeting, and I will nod off for a second. I don't entirely go to sleep; my body merely seems to give up suddenly. The vitamin B12 helps me to remain focused and increases my metabolism. It is also important to get plenty of rest and maintain a moderate exercise regimen in order to maintain energy levels.

Inflammation is the most common symptom of lupus to be treated by natural or alternative remedies. Eating omega-3 fatty acids, found in fatty fish, have shown to ease inflammation. Herbal supplements, such as cat's claw, black walnut, and flaxseed oil, have also proven beneficial. Vitamin E, which is fat soluble, helps keep good cholesterol (HDL) high, while lowering bad cholesterol (LDL), and it can reduce the swelling from arthritic symptoms (PeaceHealth). Vitamin E is often referenced in the medical and homeopathic communities, in regards to lupus and treating its complications including joint pain and swelling, among others.

Glucosamine, an amino sugar, can have extremely beneficial results for joint-related, auto-immune disorders, including arthritis and lupus (Healing Naturally by Bee). Exercise can be beneficial in treating joint problems, but only when the pain isn't too severe. Working out problem joints can make the surrounding tissue stronger and leaner, allowing for more freedom of movement, and decreasing the amount of pain. Massage, yoga, and acupuncture can also relieve joint pain, and offer the added benefit of stress release. Lupus flares are frequently associated with high stress levels, so lupus sufferers should do whatever they can to keep stress levels low. I am often delinquent in monitoring my own stress levels, but I always strive to improve.

Fungal infections plague me, and many other lupus sufferers, both as a result of the disease, and of its treatments. My toenails have been infected for years, and I constantly battle other fungal infections on my skin. Colloidal silver, taken as a supplement, can be effective as an antibacterial, antifungal, and antiarthritic remedy, while also treating both the inflammatory and infection problems that can occur with lupus, according to a host of web sites including <http://www.natural-cures-for.com>.

Skin rashes can be a debilitating problem for lupus patients. I've spent days screaming, because I've wanted to rip the beat-red, affected skin off my body. Butterfly rashes--a red, flat, facial rash that goes over the bridge of the nose--often first appear when lupus becomes active. But those rashes can quickly spread to cover your entire body. Oatmeal baths, Benedryl®, and various skin lotions can help reduce itching. But preemptively avoiding the rash is, of course, preferred. A Chinese herb, Tripteryglum wilfordii--also known as DHEA, or prasterone, is an androgenic dietary supplement derived from wild yams--actually suppresses the immune system, acts as an anti-inflammatory agent, and has been shown to be remarkably effective in reducing, and eliminating, skin rashes in lupus patients (WebMD). I am eager to explore this therapy, but research dictates the administration of the herb must be closely monitored by a doctor, as some of the side effects can be debilitating and severe. It stands to reason that anything that is partially debilitating to the immune system will have some adverse effects, just like with corticosteroids.

These herbs, vitamins, and supplements are merely the tip of a much bigger alternative-therapy iceberg when it comes to treating lupus symptoms. More research into these treatments would be prudent and should be pursued.

"Case fell into the prison of his own flesh."
-William Gibson, *Neuromancer*

Some of drug therapies for lupus, beyond corticosteroids, include the following: antimalarials, immunosuppressives, anti-inflammatories, and anticoagulants (Lupus Foundation of America).

Antimalarial drugs come in many different forms and are predominantly used to treat malaria. However, antimalarial medications are one of the ways to reduce the dosages of steroids in lupus patients. The two types of antimalarials most commonly prescribed currently for lupus patients are hydroxychloroquine (Plaquenil®) and chloroquine (Aralen®). Like steroids, they help decrease autoantibody production. Lupus has many problems associated with the skin, such as photosensitivity, rashes, and lesions. Many flares can be caused simply by being exposed to ultraviolet light, and that happens to be my most common trigger. Plaquenil® helps by reducing the severity of skin rashes, and can eliminate skin lesions entirely, as in my case. Seal, a famous pop singer, suffers from lupus and has resulted in extremely bad skin lesions on his face. Most side effects are rare, and usually disappear over time; however extended use can damage the retina of the eye. When a patient is using antimalarial medication chronically, they must see an ophthalmologist at least once a year to ascertain what damage, if any, has occurred. Plaquenil, and its cousins, can be invaluable tools in limiting flares and minimizing the damage when they occur (Lupus Foundation of America).

Although steroids are extremely common in controlling the response of the immune system, other drugs such as immune modulators (immunosupressives) target the immune response directly and are another therapy used in lessening the need for high doses of corticosteriods. As the case with the case in steroids and antimalarials, immunosuppresives can be extremely valuable in controlling inflammation (Lupus Foundation of America). Also, when steroids are unable to rein in lupus symptoms without using extremely high doses, they are a viable option in bringing the patient's condition under control. As their name suggests, they come with a host of extremely negative side effects due to their basic function.

This also requires the lupus patient taking them to be vigilant about wound care, because infections can become a major problem. Many immunosuppressives were originally developed to fight cancer, and can have side effects that mimic chemotherapy.

I currently take Imuran®, generically known as azathioprine, which helps with not only immunosuppression, but the drug also fights kidney and liver damage. Side effects can include pancreatitis and hepatitis, however. Azathioprine has helped me to reduce my prednisone intake, and I look on it now as a Godsend. Luckily, I've been able to avoid the debilitating side effects, so far. Another immunosuppressive, cyclophosphamide, is taken intravenously during drastic situations. It is known to cause hair loss and sterility. Methotrexate has a side effect list as long as corticosteroids, including cirrhosis and lung infections, which are also two common lupus' symptoms, and so can be deceptive when used as a treatment (Belmont).

Lupus patients with mild symptoms can often treat the disease with anti-inflammatories, such as aspirin or acetaminophen. These patients can manage the pain and inflammation in much the same way as moderate arthritis is treated. Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) control inflammatory flares and chronic joint difficulties. In my case, I am in constant joint pain, and the NSAID Celebrex® helps me retain functionality. NSAIDs are blood thinners, and have relatively mild side effects, but can cause stomach bleeding and ulcers (Lupus Mid-Atlantic). There are also dozens of pain medications used to treat lupus that range from ibuprophin (Advil®) to hydromorphone (also known as dilaudid) for varying painful symptoms and complications. Pain should be one of the easiest problems to overcome with alternative therapies such as these.

Extended use of corticosteroids is irresponsible and damaging to the lupus sufferer. Large doses of prednisone should only be used in situations when a patient is experiencing an extreme flare, or when they are needed to bring the disease under control following initial diagnosis. After the initial use of corticosteroids, they should be eliminated, or tapered to their lowest possible levels, using the therapies described above or any alternatives that may be developed in the future.

Hope of freedom from damaging drugs does exist for the lupus patient even though no cure is in sight. BENLYSTA™ is a new drug produced by a company called Human Genome Sciences. On June 11, 2009, this company announced the results of a long-term, Phase 2 trial showing the drug inhibits the production of autoantibodies, which are attributed with attacking healthy tissues in lupus patients, and may be an alternative to corticosteroids. Their results showed the drug was well tolerated, with very few side effects (HGS). It has a long way to go before FDA approval, but it would be the first drug developed and released specifically for lupus in more than 50 years.

"'Chaos Mr. Who,' Lupus Yonderboy said. 'That is our mode and modus.
That is our central kick.'"
-William Gibson, *Neuromancer*

As a disease, lupus wreaks havoc and is unpredictable. No system or organ is safe. It's as if the disease is an anarchist, destabilizing the organs and systems of its host. More often than not, it starts with the skin. Rashes appear initially on the face, then on other regions of the body, at random. Then, it moves, without rhyme or reason, to other parts of your body. It can attack your kidneys, your lungs, and your heart severely, or it may just weaken them. It can attack cartilage, forcing the host to scratch, which creates lesions. All this chaos makes lupus very hard to treat effectively or conclusively. As the disease develops and evolves in each patient, new courses of treatment are required, and the prior treatments must be modified. Lupus requires supervision, agility, and modification by caregivers. Blood counts need to be tracked, and everything from medications to diet must be adjusted constantly. This amount of proactive care can be a burden, both on its victims and their caretakers.

During my interviews with medical professionals, doctors have shared their frustration about the limited, available treatment options. Each of them has bemoaned, "How can I care for someone who can not afford, or does not have, access to proper medical treatment?" And I know that when I was first diagnosed, in a hospital emergency room and subsequent hospital stay, I was treated the only way possible with such severe symptoms; by using high doses of corticosteroids. Once I was functional and released, I was sent out with a prescription for more steroids, as I could not afford to have someone monitor my condition. I believed steroids were the only way to keep the chaos of my condition at bay, particularly while all I could afford to do to maintain my disease was to visit a free clinic regularly. In fact, I still owe San Francisco General money for my emergency care, but that was the extent of what was possible for me; emergency care. At the time, there was no way to do what was really needed; begin a relationship with a rheumatologist who could slowly wean me off of the highly-damaging and dangerous medications, and who could slowly offer up other therapies. I had no medical insurance, and I was barely able to afford the high dose poisons I needed to function at the free clinic.

I had the opportunity to visit a support group for lupus patients where I met some extraordinary people. Predictably, most were women, but we all shared the same troubles and concerns with considerable differences. Men, however, had symptoms more severe than women. A man named James had his skin decimated by lesions, another, Steve had a history close to mine.

Steve had been fighting lupus for years before his diagnosis. Like me, he had worked in the restaurant business, but unlike me he dealt with his physical problems by turning to recreational drugs and alcohol. When he felt fatigued, a symptom almost all sufferers share, he turned to “crystal-meth” and cocaine. To deal with pain, he used alcohol to excess. He eventually came dangerously close to death and was saved by an emergency room with prolonged corticosteroid therapy. He is gay and initially doctors assumed he was suffering from an HIV infection. Steroids took their eventual toll and he now has one hip replacement and is scheduled for another. He still takes high doses of prednisone as his body reacts violently when he does not maintain a dosage of 20mg per day. He is however, entirely sober now and after hitting “rock bottom” he has been able to stay sober entirely for over three years. The abuse to his body has taken an extended toll on his physique and due to the severity of his condition there is no way to gauge what damage has been done by abuse or disease.

Another patient, Julia, was more of a success story. She was diagnosed with lupus over 9 years ago and was treated briefly with a corticosteroid regimen to bring the disease under control. When her symptoms appeared to be in remission she modified her diet and uses sunscreen habitually (sunlight can be a powerful lupus trigger). She hasn’t had a flare since but is now nervous about having the children that she desperately wants. Most women tolerate pregnancies well with lupus. My mother wasn’t so lucky. I wish her well.

Dr. Andrew G. Franks, Jr., professor of clinical dermatology and director of the connective tissue disease section of the skin and cancer unit at New York University Medical Center, runs a clinic specifically tailored to skin related rheumatological conditions. He routinely administers high doses of steroids to handle serious lupus cases, as well as other skin conditions. He does so with some reservation, as he understands the damage done in the effort to make a patient functional again. He always refers his patients to other providers for continued and sustained care, but he sees some recidivism, because he suspects the patients won't, or are unable to, get subsequent treatments required for effective treatment.

Dr. Paula Rackoff, assistant chief in the division of rheumatology, department of medicine at Beth Israel Medical Center, helps patients that have initially and irresponsibly been prescribed massive amounts of harmful medications. When I first came to her, my system had already been ravaged. She spent the first several months doing damage control. My blood work was a mess, and she had to closely monitor me while tapering me off of the dangerous medications I had been taking. Despite her best efforts, I still developed debilitating complications. She has expressed her regrets that she was not there to treatment when I first became symptomatic, and she has told me that it breaks her heart to have to try and repair the mistreated patients that come to her.

My case, and those of my fellow lupus sufferers without proper medical attention or insurance, points to a broken state of healthcare in the U.S. We need a universal system that will help those get the early and consistent treatment they need, to avoid damaging, life-threatening, and expensive care later on. And lupus is just one of myriad conditions prevalent in this country that require months of constant supervision before the patients reach a stable status. Emergency rooms and walk-in clinics do not, and cannot, provide that type of long-term care. Emergency rooms should not be revolving doors. They should be for emergencies. These sources for medical care are not set up or equipped to handle long term or preventative care. Many health problems would have been non-existent, or less severe, if there was a universal, preventative system in place. Without accessible healthcare, taxpayers pay millions of dollars every year in needless costs. Had I been treated correctly, I may still have had my hips, and many of my current and on-going infections may have been avoided. And I'm one of the lucky ones. Many people aren't so, and they suffer and die needlessly from lack of effective medical care.

My claim of policy requires that steroid use be limited to extreme lupus flares or onsets, with adequate subsequent care. Part of that care also requires that everyone diagnosed with lupus be afforded the proper maintenance and regulation of the disease. Treatments are on the way however. Hopefully we are on the verge of controlling the disease entirely.

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