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Jodi was 18 years old and having
the time of her life...

[PATIENT INTERVIEW by Diane Zimmerman, Ph.D.](#)

Jodi Norton was 18 years old and having the time of her life. A star on her high school swim team, she'd been recruited by a diving coach to join Team Orlando. She was spending her senior year in Orlando, Florida and was living out her dream of becoming a professional diver. Looking back to this time from 10 years later, Norton says she felt that nothing could hold her back, least of all her well-trained athletic body.

The first signs that something might be wrong were the extreme fatigue and occasional dizziness she began experiencing. Then a serious accident left her with a broken wrist and hand. Because the young people on Team Orlando work out strenuously- training four hours a day when school is in session, and eight hours a day otherwise--her symptoms were repeatedly dismissed by doctors as the results of "overtraining". Norton responded by pushing herself even harder. After recovering from the accident, she resumed her rigorous diving schedule and completed her year in Orlando in spite of continued dizziness and extreme fatigue.

The following year, Norton was recruited by the University of Arizona to be on their diving team. Most of her time was spent under the Grand Canyon State's clear blue skies and blazing hot sun, and her symptoms rapidly became more frequent and severe. Skin rashes and severe joint pain set in. After eight months of struggling to maintain her rigorous workouts, Norton decided to leave the team and seek medical help, hoping to get a diagnosis for her symptoms.

Again a feasible explanation camouflaged her emerging lupus. Several of the team had been diagnosed with mononucleosis, and Norton was also found to have the antibodies for the virus. This time, Norton had to leave the team and drop half of her course load in order to cope. She was treated for mononucleosis, but the symptoms did not subside, and the search for a diagnosis continued.

One doctor who suspected lupus referred Norton to the Mayo Clinic for testing. The tests came back negative-possibly due to the high dose of steroids she was taking for a dangerously swollen throat.



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Nothing could hold her back

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During her second year at the University of Arizona, Norton refocused her career direction. Instead of subduing her, the obstacles to her athletic ambitions instead became an inspiration to acquire medical knowledge, and in 1993, Norton transferred to a premed program at Columbia University in New York.

After only a few months at Columbia University, she had an even more severe onset of symptoms--or "flare"--and entered the emergency room at Mount Sinai Hospital with overt symptoms. She had been off steroids for a while at that time, and a definitive



diagnosis of lupus was made by the ER physician. At first, Norton was flooded with relief. For years, people had been puzzled by her complaints, and some implied that the disease might be "in her head." Now at last, there was a diagnosis, and hopefully, treatment. The team at Mount Sinai referred Norton to a rheumatologist, who began treating her flares with prednisone. These episodes reoccurred about once every three months or so, and after an initial high dose, the steroids were gradually reduced.

In November of 1994 however, Norton confronted the potential severity of lupus. She was hospitalized with severe chest pain and difficulty breathing and was diagnosed with pericarditis. The pericardium is a thin layer of tissue covering the outer surfaces of the heart; this tissue had become inflamed. The pain was most severe when Norton lay down and could only be relieved by leaning forward in a sitting position. Again, a high dose of intravenous (IV) steroids brought the inflammation under control.

Two months later in January of 1995, Norton had an even more severe episode. At the time she was still diving, and she began to feel a terrible dizziness in some of the moves which involved a twist in the air. The dizziness persisted and was soon accompanied by severe headaches and stiffness and extreme pain with eye movements. She had developed aseptic meningitis, an inflammation of the thin membranes covering the brain and spinal cord. Her symptoms were those typically associated with lupus, but with increased severity: rash, fever, drowsiness, severe headache, stiff neck, and sensitivity to light.



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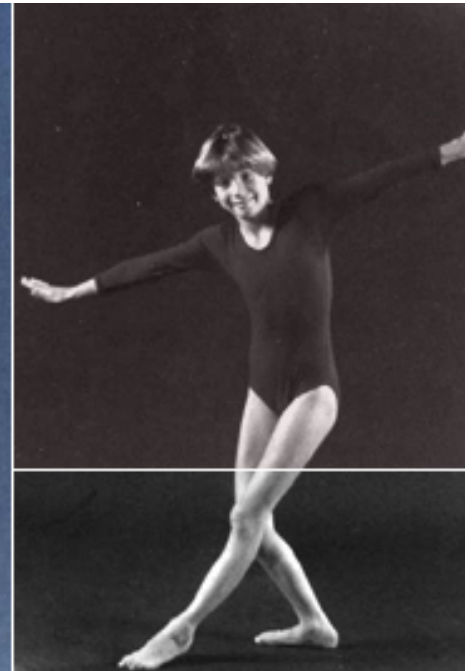
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A Deep Passion for Life

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This was Norton's first indication of a more serious involvement of the central nervous system. If left unattended, meningitis can produce permanent neurological deficits such as seizures, motor abnormalities, and cognitive dysfunction. Again the treatment involved a high dose of IV steroids, and this time Norton was forced to take a medical leave of absence from her studies. Upon returning to Arizona to spend time with her family, Norton was subsequently diagnosed with Lyme disease, and the treatment involved IV Rocephin. After spending a few days in the intensive care unit, she was sent home with a peripherally inserted central

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catheter-a PICC line, through which she could self-administer the necessary medications.

Norton returned to Columbia University to resume her studies the following year, but again had to deal with a symptom of her disease called papilledema, an intense swelling of the optic nerve. Again, she was treated with steroids and the lupus was kept at bay long enough for her to complete an undergraduate degree in 1999, although not in the premed program she had entered. Still avidly interested in pursuing a medical career, Norton's next step was to enroll in a Post-Baccalaureate Premedical Program at Bryn Mawr College.

By this time, at the age of 26, Norton's lupus episodes had become increasingly severe and frequent. Since her first episode in 1995 and over a period of five years, Norton had had four episodes of aseptic meningitis. In the summer of 1999, she began experiencing excruciating headaches and had wrist drop, a joint specific loss of muscle control resulting from the neurologic involvement. An MRI (magnetic resonance imaging) revealed a brain stem lesion, and Norton was treated with IV steroids along with monthly chemotherapy treatments of Cytosan (an anti-cancer drug that works by suppressing the immune system). Norton's treatment also included a course of intravenous immunoglobulin therapy to assist her weakened immune system in the fight against infection.

Norton, now 28 years old, is currently living at home in Arizona while she recovers from her latest bout with lupus. When asked how lupus has affected her personal life, Norton said that her friendships have changed dramatically. Many of her previous friends had little understanding of her problems, and because Norton continued to look extremely healthy and athletic throughout the ravages of the disease, her friends had a tendency to ignore or discount her disabilities. These days, Norton finds that her closest friends are those who have experienced similar physical problems, or who have loved ones who have dealt with painful diseases.

Norton has now been on a steady dose of steroids for three years, and has learned to anticipate lupus flare-ups at an average rate of one per month. She has made her struggle with the disease an inspiration for learning, and plans to study the medical specialty immunology. When asked what her advice to people newly diagnosed with lupus might be, her answers were:

- Educate yourself about the disease; it is much easier to wage war against what is known.
- Talk, talk, talk to others that share your situation. Find support groups and talk some more.
- Maintain a current list of your medications and your known allergies.
- Above all, keep an accurate and complete synopsis of your medical history, including copies of all your test results. These will be helpful to your doctors in providing baseline parameters and other crucial information needed to diagnose and treat new lupus episodes and will hopefully eliminate a need to repeat tests or perform unnecessary one.

Norton's story is one of empowerment and a deep passion for life and learning. In addition to pursuing her own career in medicine, she is helping to establish an organization named Lupus Inspiration Foundation for Excellence (L.I.F.E.). The organization's purpose is to promote awareness of Systemic Lupus Erythematosus (SLE) and to provide financial and educational assistance to college students with the disease. College degrees are often more difficult for individuals with Lupus to attain; many individuals with organ-threatening disease must delay school or drop out altogether. Those who are able to attend may need to reduce their course load. This part-time status places a substantial financial burden on any student, since most financial aid or scholarships are given only to full-time students. The Foundation realizes the obstacles a student with Lupus faces, and was created to help these students achieve their academic goals by providing financial and educational assistance. Every year the Foundation will select students to receive The L.I.F.E. Scholarship who have demonstrated courage and perseverance in their struggle to overcome the limitations of Lupus.

