

## Ellen, daughter (Nicole) diagnosed at age 22

**Our daughter** has had lupus (SLE) for over 10 years now. She is only 32 years old. Nicole was diagnosed with lupus in September of 1996. The first signs were aching joints, followed shortly thereafter with the butterfly rash. The first time she went to the Dr. about the aching joints, they told her she either had Rheumatoid Arthritis, or Lyme Disease. Tests revealed it was not Lyme Disease, so they figured she had RA and there wasn't much they could do for her. When the pain got so bad and she couldn't stand it anymore, she went back to the Dr. They did more tests, and came back with the diagnosis of Lupus. She made an appointment at Gunderson Lutheran Clinic in La Crosse, WI, to get better care, and find someone that understood the disease better.

In Feb 2001 the unthinkable happened. The lupus attacked her kidneys. She underwent months of chemotherapy, and was able to beat it. The one thing in the whole world she has ever wanted was to be was a Mother, but the chemotherapy left her sterile. At this point even adoption is even out of the question.

While under the care of Gunderson Lutheran Clinic, she also participated in a study, to help her cause and others who have lupus. Her and her husband moved to Stewartville, MN, bought a new house and started new jobs, just one year ago. Stewartville is just 10 miles from Rochester, MN. She was able to get referred to the worldly renowned Mayo Clinic, in Rochester, MN. She has had several flare ups, where she is laid up for a few days, but this last flare was indeed the worst that she has had in the 10 years she's had lupus.

On Oct 13, 2006 she walked into the emergency room at Olmsted Medical (Rochester, MN) to be treated for what we thought was a migraine. In Triage her body temperature was 103.5, and not only did she have a severe migraine, but also severe stabbing pains in her hips and lower back, so bad she couldn't stand, sit or lay down without being in excruciating pain. She shook uncontrollably from the fever and the pain. The doctor on call thought she might have a kidney infection, and admitted her to the hospital. She had a very torturous night of excruciating pain in her back.

On Oct 14, 2006 her temperature reached a very scary 105 degrees. They put her on morphine for the pain and continued to run tests. By the afternoon she had a tingling feeling in her feet, which quickly spread up her legs and into the pelvic area. All of those areas soon became numb, and she couldn't even wiggle her toes let alone stand or walk.

On Oct 15, 2006 Olmsted Medical transferred her to St. Mary's Hospital (Mayo).

On Oct 15 - 19th there were more and more and more tests only to find all of them coming back negative. At this point she no longer had the feeling of pain in her hips or back. They finally surmised it was a lupus flare that had attacked her central nervous system. She was given massive doses of prednisone, and started on Cytoxin.

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On Oct 20 & 21 They started physical therapy on her, which was not showing much progress at all. She could wiggle her toes, and if sitting on the edge of the bed, lift her legs upwards an inch or two.

On Oct 22 the doctor told her he would like to have her go through a plasma exchange, to give her body the boost it may need to get going again. This involved a simple surgery procedure to insert a blood line catheter into her neck, which stayed in until she had all 6 plasma exchanges, one every other day.

On Oct 23 she had her first plasma exchange, and she tolerated it very well.

On Oct 24 for the first time since the 14th of Oct she was able to set herself up on the edge of the bed and dangle her feet, and with help for balance she was also able to stand on her feet.

On Oct 25 her Dr checked in with her, and asked her if her ears were ringing the day before. Nicole said no, why? She said that the Drs. had their monthly staff meeting and she was the main topic of the meeting. She also told her that of all the people in the world that have lupus there are less than 50 cases of her type. I had to at this point ask myself, why my daughter? She was released from the hospital on November 4th. With the help of her husband and using a walker and a wheelchair, she was able to ambulate around the house. Since then due to physical therapy and her determination, she now gets around with only a cane. She has come a long way since she was first hospitalized, but no one knows at this point, how much she will get back. She still has numbness in her legs and feet, which affects her balance.

I have not shared the following fear of mine with anyone else, but, where will the lupus decide to attack next? I am truly very scared for her.  
Thank you for letting me share my story.