

# Susan's Lupus story

**Susan has Systemic Lupus Erythematosus (lupus), an autoimmune disease where the body mistakenly attacks health tissue. It can affect the skin, joints, kidneys, brain, and other organs. Susan has been a patient at Manchester Royal Infirmary for almost 20 years and has taken part in a number of different research studies.**

I had an inkling something was wrong in my late teens when I started to have problems with my health, including joint pain. After three years of tests I got an official diagnosis from my doctor, who told me I had lupus. I had never heard of the disease and did not understand what it meant or how it would impact my life.

Over the next 10 years I was able to control the disease somewhat with a mixture of immunosuppressant drugs and anti-phosphorus medication. When I was diagnosed I had initially been told it would be difficult to have children, but I was blessed to give birth to two healthy boys who are now 17 and 18 years old.

Unfortunately through my second pregnancy I experienced a serious flare up of my lupus and this continued on and off for years to come. I would spend days without being able to get out of bed; my body was gripped with pain and stiffness leading to a number of complications such as cellulitis, arthritis and Raynaud's disease. This had a major effect on my family, work and social life.

It was around 2004 when the immunosuppressants stopped working and my consultant tried me on various other drugs, which worked to varying degrees. I was then lucky enough to be one of the first patients to be put on rituximab, a new biologic treatment, which has transformed my life.

The effectiveness of the treatment has meant I have been able to go back to working full time, managing my own business, as well as enjoying getting out more on long dog walks and seeing friends and family.

I first found out about research through my being a member of Lupus UK and through conversations with my consultant, who is passionate about advancing medicine. I know that without research, drugs such as rituximab wouldn't be available so I was eager to get involved.

My reason for taking part in research is not only to help my condition but help future lupus patients going forward. I have taken part in various studies, with the most recent one involving an MRI scan. The study is looking at how the brain works in people with lupus, focusing on memory and concentration problems.

What I've come to learn through my experience of research, is that it isn't all about discovering new drugs and treatments. Scientists and doctors are working together to develop a better understanding of the disease, how it can be treated, managed and most of all how it affects people lives.

*Research helps create a positive environment for patients, encouraging us to look into the future and look at how we can overcome obstacles such as disease management and psychological side effects. I believe in having a positive attitude*

*towards life, even if there are hurdles along the way. Above all I am determined that my condition is never going to get me down and with the help of medical developments, I won't let it win!*

## **Learn more about our research**

**Hear more on our research into Lupus looking specifically at memory and concentration problems from researcher Michelle Barraclough [here](#).**