

My Sarcoid Story – So far

I am 28 years old from Glasgow and I was diagnosed with Sarcoid in Feb/March of 2006.

I initially went to my GP about large lumps in my neck and chest/lungs and she immediately told me it was likely I had Hodgkin's Lymphoma, obviously I was very shocked and upset and sent off for tests. I had blood tests, x-rays, CT Scans, needle biopsy, core biopsy and lymph node removal under a general I was told throughout I had cancer and Chemo or Radiation therapy would be used. They then got the results of the Lymph node removal and found granulomas.

I was then told it was TB, I subsequently failed the TB test and they moved on to lung function tests and a lung bronchoscopy Biopsy. After 6-8 weeks of poking and prodding and miss-diagnosis and worry I was told I had Sarcoid Disease and was told to attend my local TB/Sarcoid clinic.

I started on Prednisolone 50mg per day and also was given calcium tablets and other tablets to help with severe indigestion that seemed to follow as a side effect.

To date I moved down to 30mg then 25mg then 15mg and then 10mg and it seems the lumps in my neck had gone down but I was feeling much worse than before I started on steroids. X-Rays have shown that the lumps in my lungs have not gone down at all and 2 weeks ago my lumps returned in my neck and I had to go back up to 25mg again. So as I write this I don't feel I am moving forward and have been struggling a lot with breathing, eating, sweating and tiredness. Not really sure which things all relate to sarcoid and which relate to the steroids or if un related!!

I am back to hospital next week (29th August 2006) for lung function tests, X-ray and blood tests. Not sure what will happen, as it seems the steroid dose is not working properly.

As with most people on Steroids I have found weight gain an issue, I put on well over a stone in the first few weeks and have been trying to lose weight ever since but it is so hard and I find that some of my family and friends don't fully appreciate how hard it is. I feel some of the people close to me have the "But you don't look sick" attitude and because of this I feel isolated at times and don't want to complain.

I get aches and pains in my chest, often very painful stabbing pains and feel short of breath when I try and talk for a long time or if I get in a debate/argument I seem to go red and find breathing pretty hard which is weird.

I know people have it worse than me and it is a shame that more information is not available. I only recently found out about SILA and hope to do what I can to help them raise awareness for others. I was told very little about the disease when I was diagnosed and it would have been great to be aware of this site.