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S.I.L.A. NEWSLETTER 26 WINTER/SPRING 2010

Dear SILA Supporter,

I begin as usual with 'Dear SILA Supporter' and not 'Dear Member' because there are many people who are not members, but support SILA with donations, fundraising and in many other helpful ways.

The most important new information in this newsletter is that a £10,000 donation has been made by SILA into a research programme at the Royal Free Hospital, London NW3. Here is a brief description of the research that is being supported.

Immune Signatures in Sarcoidosis, Tuberculosis and Other Lung Diseases

The research uses cutting-edge technology using microarrays, which measure the unique product released by every activated gene, and that now allows identification of the patterns of gene activity that represent the human immune response. The information obtained enables the researchers to start determining which immune genes are associated with specific conditions.

Subjects are drawn from the clinics of the Royal Free Hospital. To plan this study Dr Anne O'Garra, a world renowned immunologist based at the National Institute for Medical Research, London collaborated with Dr Huw Beynon, a leading specialist in sarcoidosis and rheumatological medicine and Dr Marc Lipman, a specialist in tuberculosis and respiratory academic medicine. Dr Chloe Bloom is undertaking this as her PhD, and will be the main researcher on this project. She is also funded by the UK Medical Research Council.

There is ethical approval from the UK Research Ethics Committee to run for five years. However, it is expected that the research will continue for some time beyond this date

We hope to continue supporting this research and other new research projects in the year to

come. If you feel inclined to make a donation to SILA, as we are a charity we can benefit from tax via Gift Aid, but you will have to tell us when you are making your donation that you are making a Gift Aid donation, or if you prefer, you can contact me and I will send you a form.

When donations for SILA are given, it is usually stated that the money is to go towards research into sarcoidosis, and I often have to say that this is part of SILA's aims but a substantial amount is needed if the research is to be of lasting value. This donation was only the first step. We have accumulated some funds, and it was decided at the AGM, that from 2010 an annual donation will be made to aid sarcoidosis research. The money has been donated from those who run the marathon, half-marathons, sponsored cycle rides, and walks, dress down Fridays at work, and many other enterprises, and despite the credit crunch the

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Andrew Ferguson, Assistant Editor.



donations added to SILA subscriptions continue to be sent. Many donations are also made in memory of loved ones, instead of flowers at a funeral.

Gilbert Barr Jr.,

I am sure that everyone will be sad to hear the news that Gilbert Barr Jr., Author and Patient Activist died at the age of 51 at Southfield, Michigan, USA on Christmas Day. His death was due to complications with his longterm battles with sarcoidosis, related diseases and cancer.

Condolences were sent on behalf of SILA to Gilbert's family and friends and from Martine Caitlin, Chairperson of the Sarcoidosis Awareness Society.

Gilbert was a valued supporter of SILA and in his book *Sarcoidosis & Other Chronic Health Conditions* there is a section entitled *Across the Pond.....* which is about my life with sarcoidosis and my work for SILA. I have autographed copies of all Gilbert's books, which also include *Me and Sarcoidosis* *A Lifetime Partnership* and *A Patient's Voice*. Reviews of these

books can be found in the SILA newsletters. I think that all sarcoidosis patients could buy Gilbert's books or make sure that at least one copy is in their local public library as this would be a fitting legacy for Gilbert as well as the request by his family for a donation in Gilbert's name to either a sarcoidosis or cancer charity and to support cancer and sarcoidosis awareness.

Gilbert's funeral was held on January 2nd 2010. I hope that his life will inspire many more to become Patient Activists

I gave a talk on sarcoidosis on October 28th 2009. The invitation to speak came from the Community Occupational Therapist team to assist their Continuous Professional development (CPD) at the London Borough of Lambeth, Adult and Community Services at Hopton House, Streatham, London SW16.

I was contacted recently by Kate Hebden, Assistant Producer at SHINE TV who is making a pilot programme for the BBC to be called 'Diagnosis'. Kate Hebden wanted to meet two patients presenting with differing symptoms. One would be a newly diagnosed sarcoidosis patient. I passed this request to Martine Caitlin, the SILA webmaster so that the widest awareness for SILA and sarcoidosis groups would be achieved. I am sure that this pilot programme will be a great boost in raising more awareness for sarcoidosis patients.

I have been sent details of efforts made for SILA and sarcoidosis by member, Richard Coultman who has been writing letters to raise awareness of sarcoidosis, to many people, including the prime minister. I hope that more sarcoidosis patients will write to their MPs and other influential people, to raise awareness of living sarcoidosis and their individual problems. I hope that everyone will continue to send in their stories for the Patients' Stories pages of the newsletter.

I hope that 2010 will be a year of better health for everyone.

Heather Walker,
Editor

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The long piece in this issue of the SILA Newsletter (p. 17) is based on a September 2009 article in the British Medical Journal pertaining to sarcoidosis. The information is supplemented by text from an article in the Journal of the American Medicine Association, published a few years ago. Thus this article reflects fairly current thinking in the medical profession. From it, it is apparent that many, perhaps half of cases of sarcoidosis are identified while they are not symptomatic. About 60% of these recover spontaneously. It also appears that the medical experience is that almost as a high proportion of those who are symptomatic recover spontaneously. Moreover because there is no harmless treatment for sarcoidosis, doctors tend to tell patients that there is a good chance that the disease will go away spontaneously. It is evident that the great majority of those on the SSC network are having such severe problems that doctors need to at least try some of the drugs like prednisolone, with all its potential for unwanted side effects, so it would seem that a large proportion of patients are reassured by their doctors and don't make the effort to find a sarcoidosis social network. *Jim's Story* and *Martine's Story* are both rather dramatic, and they give a lot of valuable information about the sort of problems that arise from lack of knowledge within the medical profession generally. However, I would not want readers who confine themselves to these two Stories to think that the experiences are normal.

Patients on the SSC often mention having had lung function tests. Little does it seem to be appreciated how wide that range of tests can be. The most simple test uses what is called a spirometer. The patient blows into a tube and the electronics of the machine calculate such items as the amount of air that you are breathing out and the amount that you managed to breath out in the first second. It should be easy to ask for a copy of the print out from the machine, but in order to understand the readings you need a bit of background briefing. That is given on page 27. Incidentally the other lung function that is sometimes measured, although not often if the SSC experience is a guide, is the diffusion of oxygen through the permeable membrane, and also the volume of the lung that is participating in the diffusion activity. An alternative way at getting at the same matter is the non-invasive method of measuring oxygen saturation with a fingertip oximeter during exercise. But that will be a subject for treatment in the next SILA newsletter.

As Heather mentioned, Martine Caitlan and some colleagues have started up a Sarcoidosis Awareness Society which has already achieved a commendable amount in reaching towards its objectives. Page 28-29 give a full account of progress so far.

So that is the what we have in this issue. It only remains to thank those who put considerable

effort into writing their stories, and to Martine and Charlotte for giving us the S.A.S. progress report.

Andrew Ferguson

Jim's Story

Sarcoidosis emerged like a change in the seasons until it finally dawned on me that I was ill and had been for some time.

During 2005 I had felt 'not right'. Strange aches, pains and feelings had led to a colonoscopy, blood tests and trips to see ENT (ear nose and throat), dermatology and neurology consultants.

I had some excruciatingly anxious waits for test results not helped by a rather naïve and haphazard entry into the world of Dr Google. Exploring my symptoms online convinced me that I was suffering with any number of scary illnesses from motor neurone disease to HIV and stomach cancer.

But nothing seriously wrong was found. I felt certain that they'd labelled me a raving hypochondriac, and with my mind, work and family life teetering on the brink of collapse, I was beginning to wonder if they were right.

So when I developed a chronic dry mouth in the spring of 2006 I delayed going to my GP.

I drank copious amounts of water, constantly chewed gum and even started to swill lime juice to try to stimulate some sort of saliva production.

I was unable to live normally. I could not make long phone calls, take part fully in meetings, eat anything without drowning it in sauce or even go for a run (fitness was/is my big stress-release).

A quick 'Google' pointed to my salivary glands packing up. This also explained an odd swelling I'd noticed between my ears and jaw line on each side of my face.

I finally plucked up the courage to go back to my GP. She thought it was hay fever – something I have never suffered from – and prescribed a nasal spray. When I pointed to the swelling on my face she incorrectly said that they were not my salivary glands! – that was to be the first of a string of errors and oversights that would both frustrate and frighten me over the next three years.

Work and family life were suffering badly. I asked for a referral to a private consultant in oral maxillofacial surgery – someone who actually knew where the salivary glands were!

I am in the Westfield health scheme (a non profit making Trust that helps towards the cost of some medical care but not on the scale of BUPA) and the £125 consultation cost me around £25 and it was within the week.

The maxillofacial consultant transferred me to her NHS clinic and a couple of weeks later I was having a string of uncomfortable tests including a dye injected into my salivary glands which were then x-rayed and the most unpleasant of all – a piece of litmus paper inserted under the eyelids of each eye and left there for a minute – to measure moisture levels in my eyes.

The conclusion was that I had very dry eyes - I measured a zero for moisture, a level the nurse hadn't encountered before and which explained why my eyes were stinging at night and in the morning – as well as a dry mouth - and probably had something called Sjogrens syndrome, an autoimmune disorder in which immune cells attack and destroy the exocrine glands that produce tears and saliva. I was given prescriptions and advice on which eye drops to use though I was

warned these could only provide temporary relief and would do nothing to combat the cause of the problem.

I was booked in for a lip biopsy to confirm the diagnosis.

My mouth was numbed and a slit was made inside my lower lip. The consultant then used tweezers to take out half a dozen small glands. I had no idea lips had glands!

The results were a surprise. They had found granulomas and it was 'probably' sarcoid. I was sent for a chest x-ray and a blood test of my ACE (angiotensin converting enzyme) levels – a sometimes indicator of sarcoid activity.

My lung x-rays were fine but my ACE levels were elevated; sarcoid was confirmed. I am told a lip biopsy is a fairly rare route to diagnosis – in some ways I had been lucky.

By coincidence during the 6 months it took to get the diagnosis, my dry mouth had improved, though my eyes had become more troublesome and were so dry that I could no longer read or watch television after about 8pm. Despite trying half a dozen types of eye drops, often in large and frequent doses.

In this condition I was discharged.

This troubled me. Everything I read suggested that I should be having follow up checks from both an eye specialist and a chest consultant.

I went back to my GP surgery, though this time to a GP in whom I had more faith.

She knew little about sarcoid – and was professional enough to admit it – but she knew enough to be surprised and concerned that I'd dropped out of the system.

I was referred to an ophthalmologist – who I saw privately to save time – and to a chest consultant – whom my GP had researched as probably the most knowledgeable person of the overall picture of sarcoid in the area.

The ophthalmologist examined my eyes with a slit lamp and put some brightly coloured orange dye in to check for dryness and damage to the surface of the eye.

He then inserted a tiny silicon plug in one of the tear ducts in each eye to stop what little fluid I was producing, from draining away.

I had been using copious amounts of eye drops with little effect. After trying many different types I settled on Viscotears, which you could only use so many times a day, Hypromellose, which you could pour in as often as you liked, and a gel at night that was meant to be longer lasting. Although I found drops provided some temporary relief, I began to wonder if they were actually making my eyes worse.

I still feel I should have some sort regular ophthalmology check up on the NHS but I make up for this to some degree by having an annual eye test at a high street opticians which usually costs less than £15 (check the internet for offers). So far these checks reveal the sarc has not infiltrated the eye itself.

Meanwhile I had my first appointment at the chest clinic. I was given another chest x-ray and then asked to recall my tale of woe to a junior doctor.

He told me my chest x-ray was abnormal and prescribed 30mg steroids per day. He presented such a one-sided case that I did not realise at the time how contentious this decision was.

Naively I thought the little box of red tablets contained a tried and tested magic cure for sarcoidosis.

He didn't tell me about the severe mood swings I would suffer, the shakes, the rapid heartbeat, increased blood pressure, insomnia, the fact that steroids do nothing to treat the actual disease or

how long I would be on them, or the nightmare I would endure in weaning off them.

But I was scared, so I took the tablets and started a cycle of six-weekly lung function tests, blood tests and occasional chest x-rays. The lung tests included straight forward spirometry to check my total lung capacity and if there were any obstructions/restrictions in my lungs. In these tests I generally had to breath into tubes, hold my breath and breathe out as hard as I could, etc.

I also had more unpleasant tests involving breathing in a gas and holding my breath with a clip on my nose whilst sat in a small booth – this measured the ability of my lungs to transfer oxygen into the blood stream as far as I recall.

However fearful I was of this mysterious illness, it soon paled into insignificance.

At one of my regular visits I asked about the results of a chest x-ray that I'd had a few weeks earlier. The report had been misplaced and I was assured it would be ok anyway. I insisted it was found and it actually said there were abnormalities and I needed a CT (computer tomography) scan.

That report had been lying in the chest clinic for over 6 weeks with no action and would have been missed altogether had I not been persistent.

The subsequent CT scan results were copied to my GP surgery where I saw a young doctor. As she read the report out to me her voice quivered. She said "You've got sarcoidosis and they've found a suspicious single 8mm nodule in your lungs and you need follow up tests to see how it grows."

I was shell shocked. Sarc had been hard enough to accept but the prospect of lung cancer was something else entirely.

The next day I got a call from the hospital asking me to go in the following day to discuss the results.

Even now I find it difficult to put into words how numbed and frightened I was. I could think only of my daughter who was one at the time and our soon to be born second child. Anyone who has been through anything like this will know some of the dark places you go to in your mind.

The consultant explained that very occasionally these lumps can turn out to be cancerous and so I would need CT scans every 2 or 3 months to see how the lump grew over the next 9 to 12 months.

I found out from my own research that they do this when they make the judgement call that the risks of biopsy outweigh the chances that it is cancer. Being 38 at the time weighed in my favour.

I felt slightly re-assured but knowing I would have to live with this uncertainty for so long was physically and emotionally draining. This was on top of the small matter of my sarcoid and the daily evils being suffered by mind and body due to the steroid consumption.

I had my second CT scan after a couple of months and went to a chest clinic appointment for the results. I felt sick and was shaking. The doctor started to talk about my sarc and I interrupted and said can you just tell me the CT scan results. She was surprised. She didn't know about the scan that I'd had two weeks previously and couldn't find the results.

She said I'd have to come back in a week or so.

This is the only time I have lost it in a hospital! The CT department was 100 yards away from where we were sitting. I said I would go and get the results that minute – had she no idea what I

was going through?

She relented and said she would call me that afternoon with the results. She did and the news was steady. So far the lump was looking similar.

Three months later and I went through the same process. This time I saw the professor at the clinic and she said she thought the latest CT scan looked ok but wanted to check something with some colleagues in a different department.

My mind ran amok with what this could mean.

Two weeks later – in February 2008 – I got a letter from the consultant. My hands were trembling so much I could barely open it. She'd checked with two other professors and they were happy to say that the lump was in keeping with sarc and I needed no more scans. I was looking after my then 18 month old daughter that day. She was next to me as I read the letter. It was emotional.

At this point my steroids were down to about 10mg a day with plans to reduce further and my symptoms were well under control. Both my eyes and mouth were fine. I thought I was finally on the road to a 'normal' life. I was very wrong.

In May 2008 I suddenly developed horrendous palpitations. I'd had occasional palpitations before but this was markedly different.

Every few seconds my heart would miss a beat and then beat quickly a few times. It was happening every minute of every day and this lasted a week.

I was desperate not to go back to the GPs as I feared more tests and anxiety that would ensue – but I was left with no choice.

My GP sent for a same-day ECG (electro cardiogram). The results were abnormal. The palpitations were ectopic beats – an extra beat of the heart often followed by a pause and then sometimes a flutter of beats. They are very common in 'normal' people and can be made worse by alcohol, caffeine and smoking. I also had a possible slight left ventricular enlargement.

The GP (not the one I rate highly) gave me some advice about cholesterol and blood pressure and sent me on my way.

When I got home, around 5 minutes of 'Googling' indicated this was clearly the wrong course of action for someone with sarc.

Left ventricular hypertrophy and palpitations can be signs of cardiac sarc. I was back in panic mode and went to see my preferred GP and explained the risk and symptoms of cardiac sarc. This was not something to mess about with.

She referred me to a cardiologist and I was also sent for an echocardiogram.

The cardiologist, armed with the results of the echo, said there were some abnormalities but they could be normal for me. Yes I was confused! He said a cardiac MRI and 24-hour ECG (accomplished with a small recording device called a holter monitor) would help clear things up.

The ECG is a doddle. The hardest bit is having someone shave your chest! I even went to the gym with the holter monitor on.

The MRI was not a doddle. It was a nightmare. I was fully enclosed in a tube for a whole hour with a few inches of space between my nose and the inside of the tube and had to listen to Radio One.

The breathing exercises you have to do for this complex test made me dizzy and the whole thing was just an awful experience.

The consultant soon wrote to me to say that the results of the ECG showed more ectopic beats

and also heart block during my sleep. This is when the message is sent to the heart muscle to beat but it doesn't get there. It can also be a sign of cardiac sarc.

The MRI was essentially fine.

The tentative conclusion was that the heart block could be explained by the fact that I do a lot of exercise (it is fairly common in athletic people apparently). I was probably ok, but would need to be kept under a close watch, possible for many years.

Like most of us, I like things medically to be black and white. This left me in another grey area and dealing with more uncertainty. One of the trademarks of sarcoid. Though I appreciated it could have been much worse.

My attention returned to my battle to get off the evil little red pills I'd been taking for more than a year. I was angry I even had this extra war to fight – my increasing knowledge of sarc meant I now knew the junior doctor had erred in my case. He had jumped the gun and not followed good practice in only using steroids for sarc in certain circumstances of which mine was not one.

Sometimes my dose would go down each month; sometimes I would have to stabilise for 2 or 3 months. A daily dose of 5mg seemed to be recognised as the maintenance level. The support and guidance from the hospital on this was hopeless. I was pretty much left to my own devices and sifting through the internet for information.

I found that each time I reduced the dose I would get a kickback around two weeks later. This would usually be a return of my dry eyes and sometimes also of my dry mouth, along with some tiredness.

Such was my determination to get off prednisolone that, whatever it took, I would resolve to ride out each storm which usually lasted a couple of weeks.

I got down to 1mg a day. I was nearly there. And then BANG! I well and truly hit the wall. Even for a Sarcy, my tiredness reached new levels. The occasional afternoon naps became a daily essential. I felt light-headed and weak.

After a few days I rang the hospital who advised me to go back up to 5mg and to see the consultant.

A short synacthen test – as explained below – followed to see if my problems could be being caused by adrenal gland failure.

My understanding is that steroids take over the role of the adrenal glands in producing cortisol so these glands 'go to sleep.' One of the main reasons you must gradually reduce steroid dosages is to make sure they have time to slowly wake up.

A sample of blood is taken to give a baseline reading and then you are injected with a substance that should make your glands produce cortisol. After about half an hour another blood sample is taken to see what actually happened.

My first synacthen test was comical. I had read on the internet what the test entailed the night before but I did not expect to be advising the nurses on how to take the test properly and to have to stop them making elementary blunders.

They had forgotten to tell me not to take my steroid dose in the morning (fortunately I had guessed not to do this) they had also forgotten to order in the injection so there was a delay whilst they tried to find a doctor who could do it. They were quite relaxed about this because they had no idea that the test had to be carried out before 10am (this is to do with the body's natural cortisol cycle). I had to tell them. Then they offered me tea and coffee and food during

the test — this is something that could interfere with cortisol levels. Fortunately I knew not to take it.

The result (assuming it was accurate) showed my adrenals were being sluggish. It was sort of a relief that the symptoms were not being caused by my heart or something else. But it was also a major setback and left me wondering if I would ever get off these blasted pills.

After a couple of days of feeling sorry for myself I decided to get as fit as I could, more sleep and to try acupuncture. I have a psychology degree and a healthy cynicism of alternative medicine – mainly brought about by the astonishing experiments I have read on the placebo effect.

My GP agreed to refer me, which meant I could claim 75% of the cost back from Westfield. It seemed worth a try.

I had little belief that it would work. Once a week the acupuncturist would stick a few needles in me, then leave me in a room with some panpipe music and I would leave feeling very relaxed – at least for an hour or two.

Yet just as sarc's appearance had crept upon me, so did its leaving (at least for now).

I realised that for the first time in a couple of years a few weeks had gone by without the need for an impromptu afternoon sleep. I was working harder and longer. I had more energy for my kids – boy do you need it when they are one and three!

I am not naïve enough to think it was acupuncture alone that put me into remission (if that is what it is). There are no miracle cures for sarc. But in my particular circumstances and at that particular stage of my illness I am fairly confident it played an important role.

I think therein lies the secret to battling sarc. There is no one thing you need to do but probably lots of things that all make a small difference. And for everyone the approach and type of treatments will be slightly different. You have to find your own way.

I also took hawthorn tablets to help my heart settle (there seems to be some decent research on this though I found their effect to diminish over time) and I also take quercetin – two tablets a day. There has been one decent trial on that, which showed that it greatly reduces chest infections for those under strain.

With the sarc seemingly in abeyance I had a new positivity. It only lasted around 4 weeks.

Palpitations started again though this time they were different. My heart was missing or dropping beats. It wasn't a flutter it was simply not beating when it should.

It was happening 4 or 5 times a minute – that's over 6,000 times a day. This is not easy to live with. I couldn't sleep and even had the palpitations during exercise which is a red flag to cardiologists. Having another knock so soon was hard to take and it took all my reserves to find the fight to keep going.

My annoyance with my treatment at the chest clinic (for reasons too numerous to mention here) had been growing for some time, and so I finally decided to seek a second opinion through my GP and to get my heart re-assessed at the same time and to see if I was indeed in some form of remission.

A little research (looking at patient's recommendations on the SSC forum and Googling Prof Wells to check on his experience/interests) showed Prof Wells, at the Royal Brompton in London, to be one of the UK's leading sarc experts at one of the leading chest hospitals.

To my shock I got an appointment for 3 weeks later. My consultation with him was an eye-opener. His expertise was re-assuring – if I was very ill I would be in the best hands and

they would do all they could to answer the uncertainties about my condition.

He said cardiac sarc was unlikely but given its potential danger it was not something you took a gamble on.

I was booked in to return to the hospital for two nights and to undergo a series of tests including another cardiac MRI and a 24 hour ECG. I saw an ENT consultant (my nose had often felt blocked, been bloody, and I often had a croaky throat) who stuck a camera up my nose and down my throat, I had the usual array of breathing, blood and urine tests.

This time the MRI was done more sympathetically and with my head sticking out of the tube and the consultant even put his own copy of ACDC's Highway to hell on the headphones for me after a brief chat about our musical tastes – how's that for a personal touch.

Nervously I returned a week later for the results. This time I saw Prof Wells and Dr Oldershaw, a leading cardiologist who sees all of Prof Wells sarc patients with possible heart involvement.

Before I'd even sat down Prof Wells said 'good news your heart is ok' He told me that my tests were all looking ok and the sarc seemed to be "quiet."

Dr Oldershaw thought the alarming heart symptoms were more probably related to my exercise regime. He said if I did less exercise the symptoms would probably decline though the exercise was not damaging my heart indeed quite the contrary.

I must say I found this hard to believe at the time such was the regularity and severity of my symptoms. However the following months would show this to be correct as my symptoms did indeed improve markedly.

In summary they felt I was on top of the sarc and it would be fine for me to be looked after locally with 6 monthly or yearly checks just to be sure it was not returning.

I cannot speak highly enough of Prof Wells and the Brompton's approach to sarcoid.

For anyone who knows the Brompton, there's a pub around 20 yards from one of the main entrances. My wife and I were in there in about 10 seconds flat sinking a cool lager on a boiling hot day and feeling like crying with relief.

This is in stark contrast to the catalogue of errors and bad practice that has littered my diagnosis and treatment elsewhere including abnormal test results that I was not told about for months, and hospitals simply forgetting to call me in for important check ups.

I exonerate my main GP and also my local cardiologist as well – who is superb and has been known to email me test results at 10pm at night. He will see me again at the end of next year and may repeat some of the heart imaging tests to be on the safe side.

I was due an appointment at the local chest clinic around 4 months ago. They have forgotten about me again. This time, armed with reassurance from the Brompton, I am not going to bother chasing them.

Over the last three years I have been let down by the system and some individual doctors – whilst others have been quite brilliant, and the recently introduced right to a second opinion from a doctor of your choice is superb progress for the NHS and for sarc patients.

Despite my experiences I think it's so important not to become anti-establishment and tar all doctors with the same brush. We need them on our side and we need their help – we just need to keep a close eye on them sometimes!

I found the internet to have some fantastic information on sarc and forums offer great advice and support but they are also infected by inaccurate, misleading websites and people who, albeit

usually with well-meaning motives, will try to turn you to unproven 'cures' that can cruelly raise hopes. My advice is to tread carefully and with your eyes wide open.

Many, many people have suffered more from sarc than I have. So far, I count myself as one of the lucky ones. I still sometimes have bad days of missing heart beats (but no longer weeks and months) very occasional dry eyes but I feel better now than I have for four years and I can't remember the last time I needed an afternoon nap. I have decided not to use eye drops again unless the problem becomes severe again as I felt (without any medical evidence!) the drops did little for me and may have exacerbated things in my sensitive eyes.

At the risk of sounding negative I do not think my battle is over. Sarcoid has always dealt its biggest blows to me when I thought I had beaten it. But if it does come back with a vengeance I will be much better prepared this time.

Martine's Story

Until a few years ago I was fighting fit raising my two young children on my own, working full time as a quality manager, running five operations departments and always pushing to get as much out of the day as I could. I am also a professional dancer and fitness nut.

Things started to decline in December 2005. I was under a lot of stress with a new manager and suffered what I thought was an asthma attack (diagnosed asthmatic as a child, but never had problems), which I thought at the time was down to the stress, as my asthma only ever presented itself through stress. Thinking about it, that would have been the first time I've really been ill. I was hospitalized for a week, being pumped with steroids and given a nebulizer, and was discharged on Christmas Eve only because I refused to stay over Xmas. I was sent home with a new regime of inhalers and a management programme to prevent me having another attack.

A few months later I found a lump on my neck (March 2006), the size of a golf ball, I wondered if it was due to one of the new inhalers (as I was informed they could create sores in the mouth and throat), but after a couple of months it didn't go away, so went to my GP. I was told it was just a swollen gland; no investigations into it were done.

In the summer I started to suffer swollen feet, really bad like water retention, also my stomach would bloat out making me look heavily pregnant, which was really weird. Shortly after that I was signed off work for a few months with depression. At the time I thought it was due to the problems at work. My blood pressure was taken and was considered high, although there was no baseline as it had never been checked when I was not under stress or depressed. I was feeling somewhat tired and took the time to rest and get back on my feet. I was informed that if my blood pressure continued to stay high they would be classifying it as hypertension (the medical term for high blood pressure).

In October 2006, I had returned to work. On a doctor's visit my blood pressure was checked. It was still high, and I was prescribed blood pressure tablets to start reducing it. This was my worst nightmare, as my mum was hypertensive and I never liked the idea of taking these tablets. Almost instantly I developed a persistent cough, a lot of the time it sounded like I was choking, and I felt that I could not draw in air. Office members used to cringe when they heard it. At least it got me out of phone calls! I returned to my GP after a month and told him about the cough. I was informed this was a reaction to the blood pressure pills, so he changed the prescription and off I went.

A few weeks later, the cough hadn't gone; it had got worse and I'd started getting spasms and cramps in places I never thought you could get them, being doubled over for 20-30 minutes at a time, standing at the supermarket and suddenly can't breath from the spasms in my stomach and under my ribs, not being able to move or release them. My GP informed me it was due to bad circulation, to exercise more. My circulation had been fine up until this point, He proceeded to give me water tablets (bendroflumethiazide). From my mother's experience I think that is automatic when you take blood pressure tablets. Why, I wonder, was I not given them until two months after I started on them.

In January 2007 I woke up one morning with severe pain in my feet, they were so swollen I

couldn't put on my shoes; they were a very nasty red colour and were burning. They felt like clubs at the bottom of my legs. I couldn't put any pressure on my feet and had a hard time getting back and forth to work. I struggled as always for a few weeks to see how it went. I then returned to my GP, who advised it was gout, and I was to change my diet from a rich food diet.

Hmmm, a single mother on minimum wage with two children to support – lucky to have one meal a day given my work load and commitments and finances, let alone a rich diet.

He ran a blood test for gout, which returned negative. My GP then advised it was because I was a middle aged woman (36) and needed to wear more appropriate shoes. At this point the pains had spread to my elbows, wrists and hands, like arthritis. This made everyone in the office laugh, (Martine puts her shoes on her elbows and proceeds round the office on her elbows, yep that works!)

Several months later, still in pain, having the daily worry of how to get around, looking after my children, crying at the bottom of the stairs trying to work out how I'm going to get up and down stairs as now I have no strength in knees, hips, wrist and hands and feet, as soon as I tried to apply pressure they just give way. Getting in and out of the bath was murder. At this point all I could do was use every ounce of mental energy and use a method of mind over matter, telling my brain to move what I needed moved, a slow process but it worked enough to get from A to B.

After months of this, I remember it clearly, April 2007, it was just after Easter, I woke up to the fright of my life. My alarm goes off and I open my eyes. I was paralyzed on the bed, numb, and can't move any part of my body. I couldn't even yell to my kids to call someone. I just had to lie there, eyes open and screaming for help in my head. To this day that memory is embedded and will haunt me.

I lie there for about 20 minutes using every ounce of brain power I had to overcome the feeling and move. My daughter called my mum who then called the doctors for an appointment. It took me two hours to get to my GP which was only a 10 minute walk. Typically my doctor was not there, (never was) so I had a registrar doctor, to whom I had to explain the problem, in tears. I'm told it was a viral infection and to take anti-inflammatories and pain killers to help. That seems to be the typical reaction when doctors don't know what's wrong: 'VIRAL INFECTION'. I'd be rich if I charged £1 for every time I've heard that one!

Weeks later, the pains eased, still there, but at least I can move. But then came the weight loss. I thought at the time it was great, and didn't think much of it, as I normally lose weight through stress or a change in circumstances rather than food related. The stress at work was so much worse than before, but hey, I was losing weight.

Sitting there one evening I felt a pop in my nose; suddenly I lost all breathing in my nose not like a blocked nose it was a very weird feeling. My breathing was very bad at this point too, although I was always taking my inhalers, I hadn't noticed it so much due to everything else. Over the weeks my breathing become worse and I was feeling suffocated 24 hours a day. It was like having a plastic bag over your mouth and nose and trying to breath through a pin hole to get any air, if you can imagine that feeling. I also had very strange blistery lumps on the back of

my tongue and throat and felt like it was on fire.

I returned to my GP and was told it was a viral infection. Months later my doctor decides he doesn't like the sound of my breathing and refers me to ENT (Ear, Nose and Throat) Basildon. Hooray!!! I guess I was lucky that today was the day he felt like doing something.

In the summer of 2007 I had a rash on my neck which felt like lots of gnat bites. I was told that it was shingles, although I didn't present with any other symptoms. I then had another bout of depression in October 07 (and have not been able to work since).

I saw the consultant in October 07. He stuck a tube up my nose and told me it's rhinitis. I explain the lumps in my neck, and he says its just a reaction. He gives me a nasal spray and a form for an allergy test. Four months later I return with more lumps on my neck, face and ears. The flixonase (see list at end) pump didn't do anything. I'm fighting to breathe, and on a daily basis exhausted. He sends me for an immediate aspiration on the lumps to see what the problem is – results due in 3 weeks.

Three *months* later I'm panicking, chasing the results, speaking to some idiot on an answer phone. I contact my GP for help to get these results, thinking all must be well and not too serious as I would have heard.

Boy was I wrong! Consultant had looked at them and done nothing. But on a second look I am rushed in for an MRI (Magnetic Resonance Imaging) and CT (Computer Tomography) scan. People are jumping through hoops. I wait three weeks for those results, to be told I have lymphoma cancer. The consultant couldn't look me in the face. The following day, I have a call from the hospital asking for me to see the UK haematologist immediately (4 days later).

The haematologist tells me they have found masses in my chest, stomach, lymphatic system and brain. I'm dumb struck, in shock and total anger as this could have been found so much earlier had my GP taken notice.

Two hours after leaving the hospital I receive a call from the haematologist personally, advising me to attend St Barts in London for immediate tests and treatment the next day.

So, another CT scan, two aspirations, daily blood tests, 1 lumbar puncture, 1 bone marrow test, a biopsy, back and forth on a daily basis to St Barts, and one month later I'm told its not lymphoma after all but it could be tuberculosis or sarcoidosis. Then I'm passed to Royal London Chest clinic.

I arrive at the clinic, they all know me by first name; thought that was wicked. I was like royalty, ha-ha.

I go for a chest x-ray and more blood tests. One week later I'm diagnosed with sarcoidosis – easily treated with steroids she says. "If only they had done a simple chest x-ray" was a comment passed by the doctor on seeing the x-ray.

Now, two and a half years after the first symptom, I have my diagnosis. Incidentally when they did the biopsy on my neck lumps they were mainly looking for cancer. They found granulomas, but did not identify them as sarcoid. Sarcoidosis was only identified after the chest x-ray. So I now know what the problem is.

Do I heck!!!!

I am now fighting a battle with sarcoidosis that has attacked my brain, chest, lungs, stomach,

nervous system, eyes and lymphatic system. Apparently the various tests I have had, MRI, CT, biopsy, have identified sarcoidosis in these places; and the lumbar puncture and bone marrow tests have identified sarcoidosis in the bone and muscle.

Thanks to all those that have been battling this and have more experience and knowledge than my consultants or GP, I am now fully aware and ready for the fight; thank you to everyone at Sila.

I've been on steroids since Nov 08 starting at 40mg, this was then reduced in April 2009 to 20mg a day. My symptoms have been progressively *worse* since the start of the steroid, whereby I can't even stand long enough to run a sink of water to wash up. I suffer severe bloating such that I cannot find any clothes to fit anymore, every time I buy some, a week down the line they don't fit. I'm hoping that pretty soon the symptoms will ease and I can have somewhat of a life back.

I'm now dedicated to raising sarcoidosis awareness. Here is my drug list, with some comments regarding anything I have been able to find out about them

Predisolone - 40mg reduced to 30mg/d	An anti-inflammatory and to some extent an immunosuppressive, which at doses above 5 mg/d can have dire adverse effects.
Bendroflumethiazide- 2.5mg/d	A diuretic. "It is useful for reducing oedema (water retention) caused by heart, kidney or liver conditions, and for treating premenstrual oedema. The drug is frequently used as a treatment for high blood pressure." That is taken from the British Medical Association's <i>Concise Guide to Medicines & Drugs</i> , as all further quotes will be.
Fexofenodinehydrochloride - 120mg/d	One of at least nine different anti-histamine drugs that are used to alleviate allergies, the common uses for this variety being allergic rhinitis or skin allergy.
olmetec - 20mg/d	This is a brand name for olmesartan, an angiotensin II blocker (ARB or Angiotensin Receptor Blocker), which is used to treat high blood pressure, and incidentally used in the Marshall Protocol in very high doses as part of that protocol.
diclofenac sodium - 150mg/d	Diclofenac is an NSAID (non-steroidal anti-inflammatory drug), which like all such may have adverse gastric effects.
ranitidine - 300mg/d	This drug "is prescribed for the treatment of stomach and duodenal ulcers. ... It "is also used to protect against duodenal (but not stomach) ulcers in people taking NSAIDs, who may be prone to ulcers."

escitalopram - 5mg/d	An anti-depressant belonging to the group known as selective serotonin re-uptake inhibitors (SSRIs).
solpadol 30/500mg 2 x 4 x daily	This is a combined preparation with one of the ingredients being codeine, which is a mild opioid analgesic that is similar to, but weaker than, morphine. The <i>Concise Guide</i> says of codeine: “Other rare, adverse effects include breathing difficulties, which should be reported to your doctor without delay.”
flixonase 100mg/d	This is a brand name for fluticasone, which is “a corticosteroid used to control inflammation, asthma and allergic rhinitis. It does not produce relief immediately, so it is important to take it regularly.”
seretide 250 4 puffs daily	This is a brand name for a combined preparation which contains salmeterol, which is a “bronchodilator that is used to treat conditions, such as asthma, chronic obstructive pulmonary disease (COPD) and bronchospasm in which the airways become constricted. The advantage of salmeterol over salbutamol is that it is longer acting.”
salbutamol - 100mg 4 x daily	This is a “bronchodilator that relaxes the muscle surrounding the bronchioles (the airways in the lungs). This drug is used to relieve symptoms of asthma, chronic bronchitis, and emphysema. Although it can be taken by mouth, inhalation is considered more effective because the drug is delivered more directly to the bronchioles, thus giving rapid relief, allowing smaller doses, and causing fewer side effects.”
mebeverine 135mg 3 x daily	This is “an anti-spasmodic drug used to relieve painful spasms of the intestine (known as colic), such as those that occur as a result of irritable bowel syndrome and other intestinal disorders such as diverticular disease.”

Well that’s how I wrote up my Story in April 2009. Now for a November update.

I have seen no improvement in my symptoms despite taking all the above. My prednisolone is now reduced to 15mg/d. My additional medication is:

Colpermin 0.2ml (2, 4 x a day) – for gastric problems

Tramadol 50mg (2, 4 x a day) replacing the solpadol 30/500mg

Gaviscon (2 x a day) – due to getting very bad heart burn – acid reflux

I have been referred to the Brompton Hospital in London and met the lovely Dr Wells and his team, and it was just like meeting Santa. I felt at peace and felt I would finally get the treatment I needed. They explained they are dedicated to finding the root cause of the symptoms even if it is not sarcoidosis related. They were extremely shocked that at no stage since my diagnosis had I received a lung function test and that only blood tests and chest x-rays had been done to monitor the sarcoidosis. I have been referred to a rheumatoid specialist, Dr Benyon, to work out the problems with my pains. And Dr Jenson, a neurologist, will be investigating my central nervous symptoms. A health physiologist will be helping me to manage the stress and depression. An eye specialist too, which they said is vital for sarcoidosis sufferers. They also prescribed hydroxychloroquine (200mg/d), to see if it would help with the pain, but after nearly two months I've still seen no improvement.

In August, I had an ECG, my first proper lung function test, echo cardiogram, DGXA scan to check my bones, and further blood tests to those that were taken on my last visit. On 2nd September I saw Dr Jenson, to work through the central nervous system problems and persistent headaches. I was shown the comparison of my first MRI scan and the one done in May 09 (when I was taking 40mg/d of steroids – consequent to scan results this was reduced to 20mg/d), and was advised that the sarcoid had cleared. This is surely an interesting example of the usefulness of MRI scans. Dr Jenson also advised that headaches are a common factor with sarcoid. I was being referred for a sleep apnoea test to see if that could be the cause of the ongoing problem of fatigue. The option of taking anti epilepsy drugs were discussed if tests returned negative as the problem could also be a form of migraine, however there are serious risk factors to taking the drug. My next appointment with him is December 21st.

In October I met with the rheumatologist Dr Beynon to discuss the lack of mobility and pains in joints. There appears to be little acknowledgement of the fact that these pains have been persistent and non-responsive to drugs since they arrived overnight in 2006, because it was his opinion that my weight, gained from steroids, is the cause. As he states, coming off steroids is like withdrawal from a heroin addiction, there are going to be complications, so first thing first, off the steroids, then the weight will reduce, go from there. So I have now been reduced to 10mg/day until my next visit in December.

November 09 – I finally had my home assessment from Social Services, to see if there were aids they could provide to help me around the house. This came after 6 months of waiting. Finally, I now have a bath chair lift to help me in and out of the bath, a blow up pillow lift for getting in and out of bed, Grip rails in the bathroom and additional banisters to aid me up the stairs. This is definitely worth doing for those that have problems with these sort of things. They are there to help and are happy to assist if they can.

I await my tribunal for benefit claims of Employments Support Allowance which I have been refused twice, on the understanding I am fit for work, based on a medical report that outlined there is nothing wrong with me. My other tribunal for Disablement benefit is two days before Xmas.

I have been working hard with the Campaign of awareness, run a volunteer organization Sarcoidosis Awareness Society (S.A.S). I have had communication with Government

Department of Health, meetings with PCTs (Primary Care Trusts) and DWP, with full support from my local MP, and making good progress.

A patient's perspective on a *Clinical Review of Sarcoidosis*, by Dempsey et al., 2009

by Andrew R.B. Ferguson

The 12th September 2009 issue of the British Medical Journal (BMJ), Vol. 339, contained a six page *Clinical Review of Sarcoidosis*, by Owen Dempsey, Edward Paterson, Keith Kerr and Alan Denison. Dempsey and Paterson are from the Department of Respiratory Medicine at Aberdeen Royal Infirmary. That is something which those within commuting distance of Aberdeen might like to note.

The *Clinical Review* is addressed primarily to other doctors. The purpose of this perspective view, on the other hand, is to give Sarcoidosis Support Community (SSC) members an insight into what doctors are thinking, and hopefully to let some doctors know what a group of sarcoidosis patients are thinking. Although this is titled "A patient's perspective," I should say that I have consulted half a dozen active contributors to the SSC, so it is actually the perspective of several patients combined. I also sent it to the lead author of the BMJ Review, Dr Dempsey, and he was kind enough to reply with some useful comments, which of course have been incorporated.

The review says that more than 90% of sarcoidosis patients have lung problems. That seems to be based on secure statistics. The 2003 ACCESS study in the USA reported that 197 out of 215 patients had lung problems at presentation, and another 3 developed it during the observation period. The percentage might be even higher if asymptomatic patients were to have been included. Anyhow my problems are — now at least — primarily lung problems, so I was particularly interested in the following regarding assessment methods:

The severity of lung disease, disease progression, and response to treatment are assessed by spirometry, gas transfer, and an exercise test. They may be normal in milder disease, but spirometry typically becomes restrictive in pulmonary fibrosis (although it can be obstructive if there is endobronchial involvement). As the disease progresses, gas transfer may be impaired and exercise associated desaturation may occur.

"Restrictive" generally refers to difficulty in getting air into the lungs, and "obstructive" to getting it out. My spirometry readings are possibly typical of chronic lung sarcoidosis. The most recent reading, and that five years earlier, are closely similar with respect to the predicted values, which would appear to indicate a stable condition. The last one, 17 Sept 09, showed a Forced Vital Capacity (the maximum amount of air one can breath out fast when really trying) of 2.44 litres, only 67% of the predicted value for my age, height and sex. The Forced Expiratory Volume in the 1st second was 1.59 litres, only 57% of predicted. Initially it seemed that spirometry could keep track of changes in my lungs, but in the past few months I have realized that poor oxygen diffusion is compounding the already fairly poor spirometry results. "Desaturation" refers to not maintaining full (about 97%) saturation of oxygen in the blood. The fact that on ascending a shallow gradient I desaturate to about 90% confirms the authors' last assertion of "exercise associated desaturation." I am still not completely clear exactly how this is assessed clinically by "gas transfer" measurements although some erudite theoretical explanations are available, but I do know that desaturation is sometimes measured during exercise and it seems almost inevitable that would involve the use of a finger-tip oximeter, because before the advent of the finger-tip oximeter measurement of oxygen saturation in arterial blood was a hard task. From Dr Dempsey's perspective of treatment, "significant desaturation" would be below 87%, which Dempsey says is the point at which he considers that ambulatory

oxygen is needed.

Incidentally the usefulness of an exercise test was also confirmed in an article on sarcoidosis in the November 2006 (Vol. 296) issue of the Journal of the American Medical Association (JAMA). Dr. Weinberger was asked whether it was “advisable to follow quantitatively the amount of exercise that can be done and the associated level of oxygen desaturation.” He said it was, even when oxygen saturation is normal at rest, and that, “One of the more sensitive ways to evaluate and follow interstitial lung diseases such as sarcoidosis is to measure oxygen saturation with exercise.” Unfortunately neither in the JAMA article, nor within the BMJ article are there indications of interpreting the oxygen desaturation figures. This seems an unfortunate omission from a patient’s point of view. In the SILA Newsletter No. 24, Mieke Neven reported that after 7 years on steroids she was invited to participate in a study being carried out by her hospital in Leuven, Belgium. She said that her group of eight included patients with pulmonary sarcoidosis, post lung transplant, and COPD, and there was quite a team looking after them, including a diet specialist, a lung specialist, and several physiotherapists. They exercised for 3 hours for three days per week. She said that after three months she felt brand new, and could do all sorts of things that she could not have done before. Sarcoidosis patients in the UK cannot expect that sort of supervision, but they can go to a gym, or purchase an exercise bicycle and finger-tip oximeter, so some guidance as to what stress to put themselves under would be useful. On my exercise bicycle, I aim not to desaturate below a 3 percentage point drop by the end of fifteen minutes. That would not apply to everyone, but I know that if I allow myself to drop to 93% and sustain that for 5 minutes my heart will start aching which I will probably feel the next day. I know one person who happily exercises at a 7 percentage point drop and does not mind dipping five percentage points below that. There are various factors to consider which I amplify at endnote .

As well as saying that lung problems affect more than 90% of sarcoidosis patients, the authors mention the main common symptoms of lung sarcoidosis as being non-productive cough, breathlessness, and sometimes wheeze. It seems, from our SSC experience, that coughs are as likely to be productive as non-productive. The apparent belief of doctors that it is nearly always non-productive may be misleading them, although Dr. Dempsey does assure me that the coughs of most of his 200 patients are fairly non-productive.

The article states that, “Inhaled corticosteroids are not beneficial as initial treatment or maintenance treatment, although they are sometimes tried in patients with an intractable cough.” There are some SSC patients who are pleased by the results of inhaled corticosteroids, but then it is very difficult to assess what is really happening due to natural variations in the disease. Moreover some patient’s problems are compounded by asthma.

Fatigue, and indeed profound fatigue, is estimated to affect 66% of ‘Sarkies’. The article does — thank goodness — emphasize what a serious problem this is for patients. It suggests that it *may* be associated with a raised C-reactive protein. But as with ACE, to be mentioned later, it would seem that this is not a certain marker.

Skin manifestations are estimated to occur in 24% of patients. There is a fine picture of erythema nodosum, showing a patient with about twenty large-coin-sized blotches on each leg. A variation of erythema nodosum is Lofgren’s syndrome, which combines erythema nodosum, arthralgia, systemic malaise, and bilateral hilar lymphadenopathy. Both of these manifestations are associated with a good chance of spontaneous recovery (as has been frequently noted on the SSC site).

A wide variety of other abnormal skin manifestations are noted, including nodules, additional

pigmentation, loss of pigmentation, and lupus pernio, the last being associated with more chronic disease. We have noted that too within the SSC,. Lupus pernio was one of the few cases that did not respond during Bachelez et al's trial of tetracyclines. That gives occasion to note that this clinical review fails to mention the successful results obtained by Bachelez et al, with the tetracyclines minocycline and doxycycline, on twelve patients for whom treatment with chloroquine or hydroxychloroquine (the normally favoured treatment for skin sarcoidosis, reported to be successful in fifty per cent of cases) had been ineffective. Dr. Dempsey mentioned that the space allowed for the article in the journal did allow dwelling on this.

Eye problems affect 12% of sarcoidosis patients. It is noted that uveitis is a sight-threatening complication, and yet patients may not always be symptomatic, so, as is often reiterated on this site, a slit lamp examination of the eyes is mandatory in all sarcoidosis patients. Later it is stated that oral steroids are only used for eyes when topical treatment is ineffective: "Absolute indications for oral steroids include hypercalcaemia [too much calcium in the blood], neurological involvement, cardiac involvement, or ocular involvement (the last one only if topical treatment has failed)." There is no mention of symptoms quite often described on the SSC site, of dry eyes, blurred vision, and floaters of various kinds.

Liver or gastrointestinal problems apparently affect 18% of patients. Interestingly they say that typically symptoms are not apparent, except that the liver enzymes are slightly raised.

Kidney problems affect only 5%. The article refers to the fact that calcitriol [we normally refer to it as the vitamin D metabolite 1,25-D] is produced by macrophages and can result in calculi in the kidneys, and other problems leading to kidney failure. On this site we have dwelt at length on the fact that doctors should be careful about supplementing patients who have a low level of 25-D (the vitamin D substance that is usually measured) because supplementation may exacerbate the problem of excessive 1,25-D. Oddly enough this article does not mention that, which is particularly unfortunate, as we have discovered that it is something which by no means all doctors know about. Dr Dempsey made the point that in a recent presentation in Vienna he gave data showing that his patients were significantly more likely to present during the dark winter months, and speculated that lower vitamin D levels might be a factor. In other words, vitamin 25-D may be beneficial until sarcoidosis becomes rampant, although at that point the macrophages in the granulomas start producing too much 1,25-D, making things worse. Sarcoidosis is full of contradictions: smokers are less likely to get sarcoidosis but sarcoidosis patients should certainly avoid smoking.

Neurological complications are estimated to affect 5% of patients, and it is recognized to be a manifestation of the disease that is more likely than others to be fatal.

Heart problems affect only 2% of patients, so it is rare, but as it can cause sudden death the article suggests that abnormalities such as palpitations or abnormalities on electrocardiogram (ECG) should be referred for specialist assessment, which may include use of a Holter monitor [24 hour check], echocardiography, cardiac magnetic resonance imaging or positive emission tomography (PET scan).

The strangest assertion in the article is that bone, joint or muscle problems affects only 0.9% of patients. The ACCESS study found a total of 5 in 215 (2%) were affected by bone, joint or muscle problems, and "bone marrow" problems affected 5%. In terms of a percentage of all patients — not only the symptomatic ones as with ACCESS — the BMJ's 0.9% appears vaguely plausible, but Dr Soskel's Sarcoid Center at www.sarcoidcenter.com puts "joints" alone at 20% to 50%. Since figures on 'organ involvement' are so variable, it would be helpful if those giving figures quoted their source (which the BMJ article does not). While I have not done any sort of

count, my guesstimate would be that somewhere around ten per cent of SSC members report muscle and joint pains. Moreover the pains suffered are often dire. It could be that in these cases sarcoidosis problems are compounded by fibromyalgia and/or chronic fatigue syndrome, both of which are associated with bad muscle and joint pains, but if so the article should have stated this and commented on it.

The authors note the need for GPs to look for potential biopsy sites, and suggest that old scars and tattoos may have adjacent granulomas. There is an illustration of just such a lesion at the edge of a tattoo.

The blood tests suggested as appropriate are manifold: a full blood count, liver function test, measurement of serum electrolytes, calcium and immunoglobulins. It is pointed out that the last mentioned can assist in excluding common variable immunodeficiency. The article does not give any guidance as to the readings that might be expected from sarcoidosis patients, and the level at which (inevitably damaging) treatment may become appropriate. One problem there is that different hospitals have different benchmarks.

It is noted that although many physicians make a check on the level of Angiotensin converting enzymes (ACE), the British Thoracic Society guidelines suggest that it has a limited role in diagnosis (something that we continually reiterate, as it can be normal even in bad cases of sarcoidosis) and does not contribute to monitoring patients when added to serial lung function and imaging.

Spirometry is noted to be mandatory for all sarcoidosis patients with lung problems. However the article fails to give any guidance as to the interpretation of the spirometry readings. The British Thoracic Society gives guidance about readings that indicate Chronic Obstructive Pulmonary Disease (COPD). Yet sarcoidosis patients can have readings that appear to indicate COPD. It seems reasonable to ask that the article should dwell on possible differences to be found in the spirometry readings of sarcoidosis patients, or even the absence of such differences.

Although it is not in this BMJ article, I think it is worth noting some statistics given in the November 2006 issue of JAMA referred to above. It is reported that in a substantial study in America, at the time of patients' presentation, the Forced Vital Capacity (FVC) of the patients with lung sarcoidosis fell into the following groups:

69% had an FVC of 80% or more of that predicted (categorized therefore as normal).

18% had an FVC of 70% to 79% of that predicted.

11% had an FVC of 50% to 69% of that predicted.

3% had an FVC below 50% of that predicted.

The JAMA article does not say whether these initial measurements were useful indicators as to what was likely to happen to the patients.

The BMJ article states that ECG is used to look for evidence of arrhythmia or conduction delay, which is stated to be useful in identifying latent cardiac sarcoidosis.

I was glad to see the authors confirm what appears to be the case in practice, that while tissue diagnosis is necessary in most cases, a clinical diagnosis may suffice in those with a classic presentation.

It is noted that there are many other diseases which also have non-caseating granulomas, and biopsy material needs to be stained to identify mycobacterial and fungal diseases. But they say that this is not a hundred per cent effective, and suggest that ideally the tissue should also be sent to microbiologists in such a manner as to allow for prolonged culture.

The article is helpful in describing the various imaging possibilities. It suggests that a high resolution computed tomography (CT) scan is a standard investigation, helping to identify

abnormal nodes for biopsy. Gadolinium enhanced magnetic resonance imaging (MRI) may be suitable for patients with suspected myocardial [the myocardium is the heart muscle] sarcoidosis or neurosarcoidosis. Imaging using the radionuclide Gallium-67 has a place, but the best of all seems to be “integrated fluorodeoxyglucose-positron emission tomography.” It is stated that “it can also be useful for monitoring response to treatment in patients with multisystem and complex forms of the disease.” There is an impressive picture showing that it can clearly pick out small disease locations from hips to the head.

What causes sarcoidosis

The article confirms that the cause is not known, and says that suggested infective triggers such as mycobacteria and *propionibacterium acnes* are unconfirmed. It says that studies of occupational risk factors are generally inconclusive, although there are some exposures that give an increase in risk including insecticides and agricultural employment. As mentioned, surprisingly smoking decreases the risk. Studies of siblings have confirmed that there is a definite genetic link.

What is the prognosis

On this site, we have often rubbished the view usually put forward by the medical profession and most sarcoidosis “information” sites that 80% of sarcoidosis cases recover spontaneously within a couple of years. This article agrees tacitly when it says that “Many patients are asymptomatic and spontaneous resolution occurs in as many as 60% of these patients.” It is obvious that if only 60% of *asymptomatic* patients recover, the figure must be lower for those showing symptoms. Elsewhere it is stated that “up to” half sarcoidosis patients may be asymptomatic. This goes a long way to explaining why *symptomatic* sarcoidosis patients see so few spontaneous recoveries, while many more such are being noted by doctors. The fact that “up to half” is probably intended to mean “nearly half” is confirmed by this information contained in the JAMA article referred to above: “In a study of U.S. Navy recruits screened with chest radiographs, nearly half the individuals found to have sarcoidosis were asymptomatic.”

Further evidence that the 80% figure is nonsense comes from a CHEST paper *Outcome in Sarcoidosis: The Relationship of Relapse to Corticosteroid Therapy* (which will be reviewed in SILA Newsletter No. 27). It showed that out of 337 patients presenting with sarcoidosis only 32% enjoyed spontaneous remission, and that was monitoring them only for four years. The overall remission figure was raised to 40% when those given steroid treatment were included.

At least with manifestations of sarcoidosis involving the lungs, the JAMA article throws some light on a question that much interests SSC members, namely how often “spontaneous remission” occurs. This is the essence of the relevant table shown there:

Stage	Hilar Adenopathy	Spread to the lungs	Presentation %	Spontaneous remission %
0	No	No	8	Not applicable
1	Yes	No	40	55-90
2	Yes	Yes	37	40-70
3	No	Yes	10	10-20
4	No	Yes (with fibrosis)	5	0

The last two columns can be combined to say that, on average, 55% (range 40 - 70%) of those who present with lung symptoms experience “spontaneous remission.” Interestingly that is not so different from the figure given by the BMJ for patients whose sarcoidosis is discovered despite being asymptomatic. As always, one must bear in mind that “spontaneous remission” means neither that the troublesome symptoms have actually got better, or that they won’t come back at some time in the future.

The most illuminating paragraph in the 2003 U.S. ACCESS study on the matter of remission of lung symptoms was when they amplified their own data thus:

These data are similar to other studies in homogeneous populations of Sarcoidosis patients. Romer found that only 13% (27/210) of Danish Sarcoidosis patients had radiographic progression over a mean of 5.5 years. Other authors have noted a similar good prognosis. Chappell and coworkers showed that 75% (112/150) of patients with Sarcoidosis referred to a single medical consultant in New South Wales had resolution of stage 1 or 2 chest radiographs over a two-year period. Nagai and colleagues showed that 68% of chest radiographs of Japanese Sarcoidosis patients cleared within 3 years. Mana and coworkers found that only 22% (35/193) had persistence of Sarcoidosis at two years as assessed by clinical features, chest radiographic findings, spirometric changes, gallium scanning, and serum Angiotensin Converting Enzyme levels.

The weakness in these statistics is twofold: (a) the situation might look different at 10 years and 15 years; (b) At a guess it would seem that only about ten percent of SSC members think of lung problems as their primary problem, and the above throws no light on their predicament. The difference in presentation of symptoms apparent with SSC members might be explained by the hypothesis that while the problems are confined to fatigue and the lungs, the medical profession reassures the patient that the problem will probably go away spontaneously, or if not it will after treatment with steroids, so few such patients bother to investigate further. Only with problems outside the lungs does the medical profession admit the full extent of the lack of knowledge that surrounds the many other manifestations of sarcoidosis, which of course encourages patients to see what they can find out for themselves.

As already observed, erythema nodosum and Lofgren’s syndrome have a good prognosis, but the article also says that, “Patients with lupus pernio, chronic uveitis, chronic hypercalcaemia, nephrocalcinosis, progressive pulmonary sarcoidosis, nasal mucosal involvement, cystic bone lesions, neurosarcoidosis, and myocardial involvement have a less favourable prognosis, as do black people and those aged 40 or more at onset.” There is not much precision there, or much comfort I regret! The article states that the disease is only fatal in 1-6% of cases, which may provide a sliver of comfort.

Oral corticosteroids

It is pleasing to see a high degree of caution recommended in using these. When they must be used, it is stated that UK guidelines advocate initial treatment with prednisolone at a rate of 0.5 mg/kg/day for 4 weeks, after which the doses are gradually reduced over the next 6 months. It is a shame that the article does not suggest what course of action the doctor should take if, as is not infrequently the case, the patient gets worse during those initial 4 weeks. Dr Dempsey says this rarely happens, although such appears to be case with several people on the SSC.

The article also suggests that to prevent corticosteroid induced bone loss, patients are usually

started on an oral biphosphonate. That is certainly advisable. We have come across several cases of severe bone damage including the need for hip replacement. Henry Shelford, who started the SSC, regretted that he had not been warned of the possible damaging gastrointestinal effects of corticosteroids, but there is no mention of that in the article. He reported that although he was put on omeprazole to counter stomach acid, which seemed the biggest problem for him with steroids, he wished that would have happened earlier as his stomach has continued to be a problem for him. It is hard to blame his doctor though: the British Medical Association's *Concise Guide to Medicines & Drugs* indicates only that indigestion is the main gastrointestinal problem that may result from prednisolone. On the other hand, the same Guide says, "Enteric coated tablets reduce the local effects of the drug on the stomach but not the systemic effects." One wonders why the article does not bring this to the attention of doctors.

As Dr Dempsey said there was not space to cover everything, and perhaps it is worth reminding readers that pages 7-12 of SILA Newsletter No. 24 were devoted to recording the experiences of SSC members with steroids. On page 7 there was a half page review of the book *Coping with Prednisolone and other Cortisone-Related medicines. They may work miracles, but how do you handle the side-effects?* by Eugenia Zukerman & Julie Ingelfinger. Heather Walker thought well of the book.

When doctors find that patients who need treatment cannot cope with steroids, they naturally look around for alternatives. Here the article is not encouraging, and neither have we been in the SSC, except that we have cited this statement from Baughman et al (2008): "For extensive cutaneous disease, the antimalarial agents have been useful. Chloroquine and hydroxychloroquine have been found to be effective in over half of the reported cases." However the BMJ article says that, "Unfortunately, no high quality evidence is available to support the use of treatments commonly cited including hydroxychloroquine, methotrexate, azathioprine, and cyclophosphamide." My own view is that there is some evidence, if not of high quality, that low doses of methotrexate can be useful as a steroid sparing agent.

Conclusion

Before going on to think about what the article has failed to say, let me observe that this "patient's perspective" has only skated over points from this generally helpful *Clinical Review*, but the overall message is that treatment of sarcoidosis is as difficult as we have always thought it to be. So even if you find doctors who are outstandingly knowledgeable in this field, you will need a bit of luck for them to be successful.

What this article fails to say

We have already observed the article's failure to take note of the use of tetracyclines (minocycline and doxycycline) to treat skin sarcoidosis, done with such success in the 12 person trial by Bachelez et al. There is another report that might have been worth a comment in view of the dire effects of all the drugs in common use, namely the report of three cases in which the patients had suffered so much with long-term steroids that they refused the doctors' normal repertoire of drugs, and the doctor then agreed to give them pentoxifylline and doxycycline, with apparent complete success, and importantly without adverse effects worth reporting.

The article is also very weak on NSAIDs. NSAIDs have adverse gastrointestinal effects and have to be used with care, but they are probably less damaging than steroids, so careful

assessment of their potential is evidently needed. Moreover some NSAIDs can be used topically, with almost no risk of adverse effects. For about a year, in 2004 and 2005, by rubbing Voltarol Emulgel P (diclofenac diethylammonium) on my chest two or three times a day I was able to obtain a 60% improvement in lung function over a six week period. Admittedly the improvement reached a ceiling, and shortly afterwards I stopped applying it (now I think the warnings on the patients' leaflet about continued use are probably overdone), and the improvement was lost over the next four months. Also after using it for about a year, in this intermittent fashion, it ceased to be nearly as effective. But there are two other NSAIDs that are available for *topical* application which need to be explored, namely ibuprofen and ketoprofen. The dearth of discussion in the article under review about the possible use of different NSAIDs seems an unfortunate omission.

In view of the very bad reaction that some patients have to steroids, it seems to me that every less harmful anti-inflammatory should be tried and studied. There is sufficient evidence that turmeric is an effective natural anti-inflammatory that I think doctors should be exploring that too, but there was no mention of it in the article. Of course it may not be the fault of those writing the article that there are these omissions, but the difficulty that doctors have in trying anything new on such a variable and unpredictable disease.

As mentioned above, "UK guidelines advocate initial treatment with prednisolone at a rate of 0.5 mg/kg/day for 4 weeks." However whether to try steroids is a very difficult decision, which many sarcoidosis patients face, so more information than this is required. I would prefer to start with about 0.1 mg/kg/day (say 10 mg/day) and see what the good effects and the bad effects were and then build up slowly, only *possibly* reaching the suggested 0.5 mg/kg/day (32 mg/day in my case). Dr Dempsey agrees that there are no studies of whether starting with a high dose is the best approach, although it is the usual decision of doctors to do this. The absence of a study seems unfortunate, for I have dramatic evidence in a different medical condition from sarcoidosis (using finasteride to treat a benign prostate problem) that what is the right, and perfectly safe, dose for most people can be an extremely unpleasant overdose for another. In view of the whole gamut of problems that steroids cause people (see pages 7-12 of SILA Newsletter No. 24), patients would surely like a comprehensive understanding of the rationale and supporting evidence for any dosage protocol that is recommended.

On a minor point, itchy skin without any visible sign is a substantial problem to a significant number of sarcoidosis patients. This is not mentioned in the article. So far we have found that people need to try all the different creams they can lay their hands on, such as "E45 itch relief" cream, or "Aveeno body lotion," because different things work for different people.

It is easy to be sympathetic to doctors who have to deal with sarcoidosis. The article states that in the UK the incidence of diagnosis is about 1 patient per year per 20,000 people. Thus if a doctor has 1000 patients, he or she should only expect to see one case over 20 years. In the USA, amongst white Americans, it is about twice as common as in the UK (although that variation may be due to better diagnosis) and seven times as common as in the UK amongst African-Americans. Even at that frequency, trials are difficult due to the many different manifestations of sarcoidosis. Incidentally, my General Practitioner had encountered three cases of sarcoidosis by time he came to retirement.

If you are hazy about the difference between "incidence" and "prevalence" the best site I know of, to explain that, and give such figures as are available, is www.sarcoidcenter.com but

“prevalence” which essentially means the number of people who currently have the disease, is obviously an almost impossible thing to measure, as people in remission may not go to their doctor for years, and their doctor is unlikely to be sure whether there is going to be a flare up in decades to come.

The United States, when has sarcoidosis “gone away”, and tetracyclines

Our friends in the United States may be more interested in what their own *Journal of the American Medical Association* has to say than the more recent views expressed in the *British Medical Journal*. Above I have introduced a few strands of thought that were voiced in the November 2006 (Vol. 296) issue of JAMA, but perhaps a few further comments would be helpful. In general, the points being made there, by Dr Weinberger, were similar. The format of the article was slightly different. It started with the statement of an actual patient designated as Ms K. Her chief symptoms were fatigue, aches, primarily in the legs, and shortness of breath. She complained of the problem often raised on the SSC, of feeling pretty awful but looking just fine, so other people tend to think you are complaining about nothing. She finished with the following words:

I guess I’m hanging onto the idea I’ve heard that sarcoidosis can just crop up and then go away. I don’t know how you actually know it has gone away other than by an improvement in symptoms. This is one of the things I would like to know more about.

Ms K did not get a direct answer to that question, but it seems fairly evident from the article, as it does in the BMJ article, that the answer is that although there are a few tests which indicate what is currently happening in the body, such as ESR (rate at which the blood cells settle), and x-ray pictures, these are only helpful. One cannot, for instance, test for fatigue (although there is a Fatigue Assessment Scale), or muscle and joint pain, thus essentially it is symptoms which are the criteria for whether the problem is in abeyance. And it may only be in abeyance: for some people there will be no return of the problem, but for others it may return either soon or far into the future. Doctors often have a problem knowing whether their patients really want to hear the dispiriting truth!

As noted, the BMJ article did not mention the Bachelez et al study of using tetracyclines to treat sarcoidosis, but Weinberger was asked a question on the use of “antimicrobials” and did refer to it when responding, thus:

An open-label trial of minocycline for cutaneous sarcoidosis conducted in France reported complete or partial remissions in 10 out of 12 patients. Even if the response in these patients was due to minocycline, which has not been proven, it is not known whether anti-infective, anti-inflammatory, or immunomodulatory properties of the drug may have been responsible.

He does not mention that all but one of these patients had not responded to the anti-malarials, nor does he mention the fact that in several cases doxycycline was used as well as minocycline. One good thing about the Bachelez et al trial is that it has been very well written up, and the five

page paper is available on the web. The trouble is that it seems to be hardly recognized by doctors. I surmise — and Weinberger’s answer gives a clue —that the explanation is they are unwilling to use any treatment unless they have a fairly clear idea of why it is working.

Interpreting spirometer readings

by Andrew Ferguson

Many people will be asked to blow into a spirometer, and without much difficulty you should be able to get a copy of the print out from the mini-computer, but maybe it won’t mean much to you. Here are my readings of FEV1 (Forced Expiratory Volume during 1 second – namely as much air as you can blow out in one second) and FVC (Forced Vital Capacity – namely as much air as you can blow out after taking in as deep a breath as possible), taken 15 April 2009, with an explanation of what the readings mean, as that is probably the best way to elucidate matters (L = litres; Pred. = predicted value. All predicted values are computed electronically – using age and height).

		<u>% of predicted.</u>	<u>Predicted</u>	<u>Pred. range: Low - High</u>
FEV1	1.48L	53%	2.80L	1.96L - 3.64L
FVC	2.13L	58%	3.66L	2.66L - 4.66L
FEV1%	69%	93%	74%	63%-86%

The only things that are actually measured are FEV1 (Forced Expiratory Volume in 1 sec) and FVC (Forced Vital Capacity); the rest of the figures are calculated:

FEV1% is calculated as $1.48L / 2.13L = 69\%$. FEV1% is not an ideal name. A better one would be the “FEV1/FVC ratio expressed as a percentage,” except that’s rather long.

The second column of the FEV1% row, is the ratio between two ratios, namely FEV1% as a percentage of the predicted value of FEV1%. Here it is calculated as $69\% / 74\% = 93\%$. Logically that seems a valuable clue (how much air you can breath out in the first second in relation to the amount you can draw in compared to a predicted value), but a doctor specialising in lungs, Dr. Howard Branley, says that the predicted value of FEV1% is not trustworthy. That is a pity, as the figures seem to tie up with my reality, namely that the amount of air I can take in is reduced, but I can still breath out what seems a good proportion of it (69%) in the first second.

FEV1, at 1.48L, is well below the *low* end of the predicted range (1.96L).

FVC, at 2.13L, is also below the *low* end of the predicted range (2.66 L). Actually that reading of 2.13L was later shown to be unrealistic for these reasons. I had not done a spirometer test for a long time, and had forgotten the need to breath in as deeply as possible. On 17 Sept, I did another test, and this time the FVC was 2.44, which was not so different from a reading five years earlier (30 Nov 04) of 2.56 litres. Moreover that early reading was 68% of predicted and the most recent one was very close at 67% (age takes its toll!). Inaccuracies, for reasons of precise effort, are a recognized problem of spirometry.

It should be appreciated that spirometers only measure the mechanical function of the lungs.

Particularly in the later stage of chronic lung sarcoidosis it becomes apparent that much of the reason for shortness of breath is due to poor oxygen diffusion. An exercise test using a fingertip oximeter to measure loss of oxygen saturation would then seem a far better measure, as it shows what can be achieved without losing oxygen saturation or only losing a specified amount of oxygen saturation, thus automatically taking into account both the mechanical behaviour of the lungs and the oxygen diffusion. Unfortunately the medical profession have not carried out tests to see if exercise testing is a better method of overall assessment than the various complex measurements that are currently sometimes used. The next issue of the SILA news will give more information about fingertip oximeters.

The Sarcoidosis Awareness Society (S.A.S.)

A progress report by Martine Caitlan and Charlotte Doggett

The **Sarcoidosis Awareness Society** (S.A.S.) is a patient-centred voluntary organisation that has been created by two chronic sufferers and a carer. They have first hand knowledge and experience of the effects of the disease Sarcoidosis, and of the lack of support and appropriate care that cause considerable distress for the sufferer and their families, both during the process of diagnosis and ongoing management.

It was created in February 09 several months after Martine Caitlan (Chair Person) and Keith Bigland (Treasurer) had been diagnosed and met on a support forum, where they found they were one of thousands who have experienced the same lengthy battles for years trying to obtain recognition for their debilitating symptoms, lack of treatment, long unnecessary tests, mishap medication and years of misdiagnosis. Their intention is to spread the word and through the awareness campaign work with government, medical and media officials to provide better understanding and care for all sufferers.

The organisation currently comprises 3 Trustees, 2 Sarcoidosis specialist medical advisers, 10 Volunteers and 65 group members. If you wish to become a member, please contact Martine or Keith on 0808 186 1886. They can also be contacted on martine.c@uksarroid.org, or keith.b@uksarroid.org. To find out the location of your nearest present and possible future SAS support group contact Keith Bigland by telephone or email.

Volunteers are vital to our campaign and for providing the much needed support groups, research and administration amongst many other things. If you would like to become a volunteer and make use of your talents and skills, and feel you want to contribute some time, doesn't matter how little or how much, every second counts, we would love to have you on board. Contact Martine and she would be happy to provide further details.

We rely on Volunteers for our support group set up, if you feel you would like to provide the time, and set up a support group within your area, please contact Keith Bigland.

The Sarcoidosis Awareness Society website <http://www.uksarroid.org> has been launched, giving useful and reliable information sources to help you understand the disease better. The Medical guidance section proposed to provide helpful guidance to those within the medical profession is still under construction but it is due to be completed by the end of this year. The public and patient section is fully completed for public use, with regular updates being made. The S.A.S. website covers a lot of information on Sarcoidosis such as the symptoms, test requirements, what S.A.S. is currently doing and what are the aims of S.A.S, also who are the Trustees and how they came to create the Organisation.

S.A.S. provide support groups within the Essex, Norwich, Liverpool and Sheffield areas with the aim to provide support meet ups nationally, allowing sufferers to come together in a relaxed environment to discuss the frustrations and problematic areas that we all face, along with providing the much needed emotional support.

The Progress Of S.A.S.

4th June 2009 - The S.A.S. handed in a Petition with over 700 signatures to number 10 Downing Street, London. This was to raise awareness about the disease, regarding which the medical profession show considerable lack of knowledge.

26th June 2009 - The SAS group in the Essex area held their first support meet up and there is to be a regular meet up every quarter. On the same day S.A.S. was awarded a small grant by the

South West Essex PCT (Primary Care Trust).

2nd July 2009 - Received a postal response from the Department of Health regarding the petition, stating that the government do understand that Sarcoidosis is a debilitating and distressing autoimmune condition [AF. Note that it is better defined as an immune malfunction as not enough is known to determine whether it is an autoimmune condition.], and that the Medical Research Council, which is one of the main agencies through which the government supports medical and clinical research, is currently funding one programme of research on Sarcoidosis at the University College of London. This University supports a large portfolio of research on inflammation and inflammatory conditions.

Basildon Hospital implemented changes for Sarcoidosis Awareness by using Martine's Story with clinical colleagues, and taking the Story to a Clinical Forum as an educational tool to raise awareness of Sarcoidosis amongst other clinical specialties, this was after she made an official complaint when she was diagnosed with Rhinitis and not sarcoidosis. It was proven through the complaint that the medical consultants failed to identify and understand from the symptoms and sight of the scans that this was a case of Sarcoidosis.

9th July 2009 – Atos- Medical Services for Benefit Assessors: established contact regarding the lack of knowledge about sarcoidosis within their assessors.

S.A.S. is currently scrutinizing the benefits system and has put both ESA (Employment Support Allowance) and DLA (Disability Living Allowance) processing and information carried on the disease into question. With the help of the Billericay Essex MPs, John Baron, we aim to meet with DLA head office early next year. John Baron has been working with Martine to obtain awareness within the local Job Centre and PCT, and by raising matters within parliament, to make the benefits sector more supportive of Sarcoidosis Sufferers.

23rd July 2009 - Established contact with London Brompton Research regarding the costs and what they are hoping to achieve with the research. S.A.S. has not received a reply as of yet but the issue is being chased up every week hoping to find out more about their aims.

28th July 2009 - MP contact re. Benefit Claimant Matters and Sarcoidosis and Procedures.

30th July 2009 - Freephone helpline number launched and activated. 0800 186 1886 Martine, Keith or Charlotte will be available to talk from 9am to 9pm, Mon- Fri. Sat-Sun, 9am-6pm (GMT Time zone). S.A.S. has received lots of phone calls from sufferers about the disease and about the next Support Group Meeting when there is one in the local area.

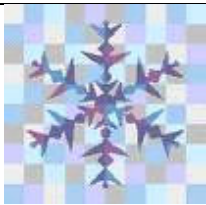
31st July 2009 – S.A.S. arranged a meeting with the South West Essex PCT about delivery of a Health Care Plan, which was held with Martine Caitlan (chairperson) and the Head of Long term conditions. The PCT has proposed a GP Workshop for Sarcoidosis. The S.A.S. is preparing a presentation about how General Practitioners can recognize symptoms of Sarcoidosis. S.A.S. welcomes a new Medical Advisor Dr. Howard Branley of the Whittington Hospital to the organisation due to his interest in awareness of Sarcoidosis. He has made some contributions to the Sarcoidosis Support Community (SSC) SILA website which is available at <http://sarcoidosis.ning.com> to which it is very easy to sign on as a member. It now has about 3,000 members.

20th September 2009 - S.A.S. welcomes aboard another Medical Advisor, one of whom everyone who has come into contact with speaks very well, Professor Athol Wells of the London Brompton Hospital (the Brompton Hospital seems to be *the* centre of excellence regarding sarcoidosis; it has received nothing but praise from those going there.) This has been facilitated because Martine Caitlan is currently under his medical supervision..

8th October 2009 – Our Website www.uksarcoid.org receives the Sarcoidosis Golden Lifesaver Award. This award is given for providing the most accurate information to Sarcoidosis Sufferers.

11th October 2009 - S.A.S. Essex area went to Swindon Half Marathon to help support two incredible people, Daniel Wilkinson and Scott Hillier, running to raise money for Sarcoidosis. This story will be told on the Sarcoidosis Awareness Society website.

For **leaflet requests**, please enclose a large self-addressed envelope together with four separate “large letter” first-class stamps to:



The Secretary, SILA
c/o Department of Respiratory Medicine
1st Floor, Cheyne Wing, Kings College Hospital
Denmark Hill
London SE5 9RS

Support Meetings are held at King's College Hospital on the first Thursday of each month except in August when there is no meeting. Enquire at the KCH Help Desk for the location of the meeting (usually the Boardroom). Meetings are held between 7 pm and 9 pm. Details of how to reach KCH are on SILA's website

SILA West Midlands Branch. This branch is run by SILA member Mrs. Carol Bashford, 38 Yew Croft Avenue, Harborne, Birmingham. B17 9TR. Contact Carol: 0121 427 5462 or email her at carol_bashford@hotmail.com for information about any future support meetings, help or advice.

The Irish Sarcoidosis Support Group ISARC is at www.isarc.ie email info@sarc.ie Mary Walters is Chair of ISARC, telephone number 01903 872416.

Information received: Travel Insurance For People Living With Pre-Existing Medical Conditions

Freedom Insurance Services Ltd.,
Richmond House
16-20 Regent Street,
Cambridge CB2 1DB

Telephone 01223 454 290 Monday to Friday 8 .30 - 5.30 pm Saturday 9.00 am - 12 noon
www.freedominsure.co.uk email: information@freedominsure.co.uk Fax 01233 720 277

Bexley Accessible Transport Scheme Unit GO5, Thames Road, Depot, Thames Road, Crayford, Kent DA1 5QJ Telephone 01322 311333 Provides transport services to Bexley residents and members of community/voluntary groups and wheelchair users. Hop'n'Shop Scheme for those over 60 a disabled person, and those with a child under 5. This service is

available for a membership fee.

Electronic version of the SILA newsletter: The SILA newsletter is placed on the Social Network site (<http://sarcoidosis.ning.com>), in Word format — in the Topic in Main Forum titled *Publication of the SILA Newsletter* — before being sent out as hardcopy. To access this, you need to join the Social Network. But at about the same time, an easily accessed pdf copy will be put on the SILA website (along with other backnumbers). This may reduce paper use, since some people are perfectly happy with an electronic version; please let me, Heather Walker, know if you do not wish to receive the hardcopy version.

Our web address. SILA's sole web address, is now www.sila.org.uk; the email address is heather@sil.org.uk

Annual Subscription to SILA is still £12 per annum. SILA welcomes comments and contributions to the SILA newsletter; also fundraising ideas or initiatives.