



S.I.L.A. NEWSLETTER 23 SUMMER/AUTUMN 2008



Dear SILA Supporter,

I hope as I have stated in last year's Summer/Autumn Newsletter that newcomers to the newsletter will not think that due to climate change that Autumn has come early this year. As with past issues of the newsletter it will come out every six months.

I was disappointed that nobody contacted me as a direct result of the request in the Winter/Spring 2008 newsletter for volunteers to help as trustees etc., but I have had offers of help subsequently which I hope I can outline in the next issue of the newsletter. One member sent me information about the Bell's Palsy Association www.bellspalsy.org.uk enclosing details of facial exercises which can help patients. This sort of information is helpful. I know it is very difficult for most members to find time and energy to volunteer. SILA continues to be grateful to Henry Shelford and his running of the SILA web-site which now has over 1,000 members in the Social Networking section..

I have applied for SILA to become a member of the Long-term Conditions Alliance (LTCA) which is free to join for the first year: www.ltca.org.uk, telephone 020 7813 3637, charity number 1057711. The vision of LTCA is of a society in which people with long-term health conditions have control over their lives and can live them to the full. LTCA publishes a quarterly publication, *Connect*, of news and views. The editor, Carolyn Townsend, welcomes contributions and comments, catownsend@blueyonder.co.uk A pdf version of *Connect* is available.

I was persuaded to take out an advertisement for SILA in the *Herts & Beds Press* in their first issue, but as far as I can tell this resulted in little if any direct response from their readers. If any member saw this issue with the SILA advertisement I would be interested to know. I was sent a copy.

I realise that it is hard for many members to cope with the day to day running of their lives. I have been sent information about a Shopping Bus Service run under the Bexley Accessible Transport System, which operates 5 days a week for people with mobility problems. Telephone 01322 333377; email bexley.ct.@bt.connect.com; web-site www.bexleyct.co.uk

I hope that the Patients' Stories will continue to be sent in alongside the letters and emails, telephone calls that need advice, leaflets etc., or to outline progress with various treatments. Sarcoidosis patients contact SILA not only from the UK but sometimes from the rest of Europe and the USA.

As usual SILA is grateful to all who renew their subscriptions so promptly. Also those who come along (sometimes make long journeys) to attend the Support Meetings. I am pleased to say that the problem about continuing to get a room for the meetings has now been resolved. Perhaps I can see and welcome you there in the future!

Heather Walker, Editor, email heather@silas.org.uk
Andrew Ferguson, Assistant Editor.



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The experiences of sarcoidosis patients recorded in the first three pieces reflect the range of symptoms that are associated with the disease (or diseases) that fall under the sarcoidosis umbrella. That extraordinary range has also been brought out in many of the contributions to the Sarcoidosis Social Network (www.sarcoidosis.ning.com) started by Henry Shelford, which now has over 1000 members. The Network has been a great success; it is much appreciated by those who have access to the internet.

Carol's story starts things off in this issue. She tells us that her consultant, "advised that my lungs were already damaged, and without treatment the condition would become life threatening." Perhaps this suggests the need for sarcoidosis sufferers with lung involvement to take more responsibility for measuring their own deteriorating lung function. It is easily measured using steps per respiration cycle.

Some people have great difficulty in weaning themselves from steroids. Good to hear that Carol did not encounter many problems, except a return of joint and muscle pain. Good also to hear that she was pleased with the medical treatment she received.

Maureen's story is an example of the fact that some cases of sarcoidosis are complicated by being mixed up with asthma and the need to take antibiotics; and that not all sarcoidosis coughs are *dry* coughs. She gives an interesting insight into the many variations on standard treatment which she has found helpful, one of them being cranial osteopathy. For those wanting to find an osteopath, the British School of Osteopathy is at 275 Borough High Street, London SE1, Tel: 0207 407 0222. She finishes by saying, "I do need to take the seretide, see the osteopath, and go to the gym, leave one out and I get problems."

David B's well-told story is next. He gives us a very full account of the relationship of his treatment to the use of steroids. How useful it would be if everyone kept such accurate records as David! His plea is for more information about muscle and joint pain.

The next piece, *Cetyl Myristoleate (CMO) and Clinical Trials*, was prompted by a suggestion that in previous issues of the SILA newsletters it has not been made sufficiently clear that the effectiveness of cetyl myristoleate in treating sarcoidosis has not been the subject of clinical trials. As well as reiterating that point, this piece gives some more background on the clinical trial that was done in 1997 on the efficacy of cetyl myristoleate in treating arthritis. Of course one cannot make the deduction that because cetyl myristoleate has been shown to be effective in treating arthritis, it will also be effective in treating sarcoidosis, but there is sufficient in common with arthritic diseases to make it slightly more likely that cetyl myristoleate has an effect on sarcoidosis.

An Interim Report On Three Cases Of Chronic Sarcoidosis, provides some evidence that cetyl myristoleate does have a significant effect on sarcoidosis, but points out that the only cases that are really suitable for study are chronic lung cases, so much time will be needed.

The final piece, deriving from Dr Chen, is a useful summary of progress at the leading edge of research. We hope that there will be something for everyone in this issue.

Andrew Ferguson

Carol's Story

In September 03 I managed to stop smoking. I had been a heavy smoker for approx 30 years. For the first nine months I felt the wonderful effects of not smoking, I could run without getting out of breath for one thing, and I generally felt really well.

In May 04 I began to feel unwell; nothing specific just tiredness etc. In June 04 I had the most awful attack of Shingles; I did not think it was possible to have such pain and strangely enough my mother and grandmother were the only other members of the family to have had this.

I was off work for about a month, and although the horrible blisters disappeared I could not shake off the general malaise. I had no energy, I could not concentrate. I had memory loss which work colleagues thought was quite funny and I would joke about. I started to have really bad back pain and then stabbing pains in my sides around the ribcage, night sweats arrived on the scene. I had a stressful managerial job; and when I sought help from my doctor she suggested I was still recovering from Shingles.

I then started to become breathless on exertion which got so bad I could not climb a flight of stairs without holding onto the handrail and resting at the top; and sometimes during 'an attack' I could not draw in enough breath to speak. I had no appetite and started to lose a good deal of weight, about 2 stones in 2 months. Then the cough started and I really thought I was dying. There were times when the coughing just would not stop and it left me exhausted. Being a past smoker, I convinced myself that I had lung cancer and went to see the doctor for confirmation.

I was sent for x-rays, and within two weeks was referred to Papworth Hospital in Cambridge, where I had more x-rays, MRI scan, blood tests and lung biopsy. The serum ACE test result was 130. I then had another consultation where I was shown the x-rays etc, and told of my diagnosis. The Consultant was sure it was sarcoidosis and advised that my lungs were already damaged, and without treatment the condition would become life threatening. Hence no choice. I would have walked around in a top hat if he had suggested it, I felt so ill.

I started on 65 mg of Prednisolone daily (this was June 05) for a month, and attended the hospital every eight weeks. This dose was reduced by 10 mgs, or remained at the previous level, depending on x-rays and ACE results. On this basis, by Dec 06 I was taking 5 mg daily (i.e. my average reduction rate was 10 mg per month); and was then advised to take 2.5 mg for six weeks, and then 2.5 mgs every other day for six weeks, (i.e. a much slower reduction rate averaging about 1.7 mg per month), and then to stop altogether. I also use an Accuhalor (Fluticasone and Salmeterol) twice a day. The Seretide Accuhalor is a combination of a preventor and a protector. The drugs contained within the inhaler are taken into the lungs and serve to relax the muscles in the walls of the small air passages, so opening up the airways which makes it easier for air to get in and out of the lungs. It lasts for about 12 hours, so it really helps with the breathing. I have been advised that the fibrosis of the upper part of the lungs is irreversible so I will probably always need an inhaler. While taking steroids I also had to take Risedronate sodium (35mg in a once a week tablet) for 'bone protection' against Osteoporosis from the steroids.

The side effects of Prednisolone were the usual: weight gain, insomnia, feeling 'spaced out', etc. But they really did relieve the cough — in about a month — and the breathlessness showed improvement after 6-8 weeks, so I felt it was worth taking them.

The pain in my chest and back stopped in line with these improvement rates, I had also been affected by joint and muscle pain for about a year before the diagnosis; I would best describe this as what I call 'back ground' pain.

Contrary to the experience of some people, I can honestly say that the side effects of reducing and stopping the Prednisolone were minimal, and not too debilitating. I would feel a little shaky sometimes, there was insomnia for a while, but I had had to cease working so I could cope with that, and I have managed to lose the weight gained. The worse thing was that as the steroid reduced, the joint and muscle pain increased to its present level which really is horrendous.

Initially I was taking 6-8 Co-Codamol 500mg tablets on a daily basis to cope with the pain. It gradually ceased to be effective. The steroid was at a level of 10mgs a day by now, and I was prescribed Tramadol, which is a far more effective pain reliever (it is an opiate), but it does make for drowsiness for about 45 mins after taking the tablets. I take 8x50mg of these a day which my Consultant advised would be a more effective 'treatment' for the joint and muscle pain as it releases pain relief in a different way, as I understand it, it blocks the pain receptors in the brain rather than the actual site of pain. I saw a Rheumatoid Consultant in June who expressed doubts about the cause being Sarcoidosis and is conferring with my Consultant at Papworth to find a suitable anti-inflammatory treatment that will not cause too great a reaction to the breathing problems.

I think I have been lucky in being referred to Papworth, and my Consultant there is supportive and caring; I am a person not a number. For the first year I attended every eight weeks, then every 3 months, and now for the first time my next appointment is in 4 months. I am however always advised that should I need to see him at any time I am to telephone and he will always fit me in. He is also liaising with the Rheumatoid Consultant in respect of the joint pain and has kept me informed of my treatment and ACE levels, which he says are creeping, back up again to 94 in March 07. Normal levels are very variable but considerably lower than this. Probably what is most relevant to treatment are *changes* in the level.

This is one hospital the NHS should be proud of. I just wish other doctors and consultants were as well informed as my consultant.

Update May 2008

Unfortunately almost as soon as the steroid was stopped the sarc flared again and by September 07 ACE levels had reached 125 and I was feeling really ill again, breathlessness, fatigue and general malaise. Steroid was started again at 40mgs daily.

At this time I also had a second appointment with my Rheumatoid Consultant who now said that after further consideration the joint and muscle symptoms were probably down to the Sarcoid. I was started on Ibuprofen to reduce inflammation and also it was thought that this would be the least likely medication to affect the breathing too much. The doctor was sympathetic but could offer no other treatment and did say that there was little more she could do.

I have managed to reduce to 30mgs of prednisolone daily and return to see Consultant in June, ACE levels have reduced again to just over 80. At this appointment we are going to try a steroid sparing agent as obviously long term use of steroids is now a concern. I have found a reduction in the levels of joint and muscle pain but worry that without the steroid it would return just as bad as ever. Trial and error seems to be the way forward for me.

Maureen's Story

I have been reading your newsletters for about the last two years, and having read all the stories, I feel I have got to write to tell you the way I am treating my sarcoidosis.

I was diagnosed with sarcoidosis in 2001 at the age of 49, after a chest x-ray which showed a large shadow. This was followed by a biopsy which confirmed sarcoidosis. I was not offered any treatment. The only problem that was readily apparent then was a constant mucus chest cough, and the consultant said just carry on with your asthma puffers, and when you are unable to go to work I will treat you.

By way of background to my asthma problem, I had bronchitis between about the ages of five and ten. It started again at the age of 25 and came back every year for the next 25 years. Treatment was with antibiotics. In 1999 I started to get wheezy and my GP gave me a puffer. Use of the puffer continued, and during the year 2000, I also had five lots of antibiotics and two 5-day courses of steroids. Nothing would cure the cough, which was sometimes a dry cough and sometimes produced mucus. The dry cough is somewhat similar to hay fever, and since 2000 it seems that it often starts with some stimulus like flowers, perfume, or grass.

In 2002 I started to get a jarring pain in my neck about every 3 months. This was a type of pain I had never experienced before. It used to build up, and then suddenly I could hardly move my neck. Over time massages sorted that problem out. Incidentally the massages were in a sunbed shop near where I work in London. I had one every three months for about a year. But just about when the neck pain was cured I started getting pain in the lower back. I had a couple more massages from the same shop, but they only succeeded in reducing the pain. Next I tried a sports massage lady, whom I saw every two weeks for almost two years. It worked for about a year, but I only had to go swimming and the whole back started to ache, albeit not as acutely painful as before. I only stopped the massages in early 2003 because the oils being used were making me wheezy.

In the summer of 2003 I got a paralysing pain in the lower back, this was successfully sorted out by an osteopath. I saw him twice a week for two weeks, but the pain would not go. Then he suggested that it was my posture, and gave me a belt to wear at work (only there, not at home or the train). This belt went round the waist and had two loops for the knees. I only had to wear it when sitting at my desk. Amazingly it worked: in two days the pain was gone. However he was concerned about my constant mucus cough. He told me to get a brick, put it in the oven for 20 minutes, apply Vick to my chest, and then place the warm brick on a towel on my chest for 40 minutes, when lying in bed, before I went to sleep. It was not a success. It did not cure the cough and seemed to make more mucus in the chest.

By 2004 I was getting the lower back pain every 2-3 months; it seemed to come on when I took a holiday. In October 2004 I went on holiday to Marrakech, in Morocco, for a week. I had just taken a five day course of steroids, which had stopped the cough, but three days into the holiday my lower back suddenly went, and so badly I had a job to sit down and get up, plus the cough came back. I still had it a week later on my return to England.

Next I tried acupuncture, but it relieved the pain for only two hours, so I knew I would need to see an osteopath. This time I got one that was near to me, out of the yellow pages, and one who was covered by all the health care people including the non-profit HSA Group Limited to which I belong. The osteopath treated the pain in the back in one session, but said I needed treatment for the source of the pain, which was the constant cough. I have seen this osteopath since October 2004, almost every two weeks, the cost being not too bad as I have HSA. After about 15 months the pain finally went completely.

The chest problem has actually disappeared at times; the osteopath has been using the cranial osteopathy method on me. He also advised that I should not have any dairy food or bread, especially first thing in the morning; this has decreased the mucus in the chest.

As mentioned, my use of steroids has been confined to five days periods. But when I switched to a new chest consultant in 2006, he offered me the option of trying a two year course, saying that if at any time I had high blood pressure or they were not happy with my health I would be taken off them immediately. Incidentally he gave me no warning about the need to come off steroids gradually. I would have had to have checks at the hospital once a month. We agreed that I was coping quite well (seeing the osteopath twice a month and going to work, etc.). So although it was apparent that the shadow on the lungs had not changed, and neither had the cough gone away, it did not seem worth risking high blood pressure. I see this chest consultant every six months at the moment, to check the shadow and have a talk. Over the last year my blood pressure has been 146/90, which is quite high, but my GP does not want to give me anything for it, as it may be the coughing which is pushing it up, and my blood tests are okay.

My new chest consultant at the hospital has changed my puffer to Seretide 250,⁽¹⁾ 2 to 3 puffs twice a day. To date, the shadow on my chest has not changed since 2001. He is concerned, as it should be fading out now, but my breathing has improved a lot over the last two years. I have had three breathing/lung tests over the last three years. They are comprehensive, lasting for an hour. The exercise is the same as walking on the running machine, which I do anyhow for ten minutes twice a week. On the last test, they said I was almost normal, at 6.0, which figures, because at that rating I could actually jog.

I have a full time secretarial job, travelling by train to London everyday, and I go belly dancing, gym, swimming and yoga, in fact out almost every weekday night. I still get the symptoms that many people get with sarcoidosis, namely a cough, and feeling tired, and sometimes short of breath. The tiredness tends to get me at about 3 p.m., while I am sitting down. Suddenly I feel I want to close my eyes. I try to shake it off, but in the end I am forced to walk around the building and talk to people for ten minutes. When I get back I'm okay.

Apart from the clinical tests, I get a pretty good idea of how my lungs are functioning because twice a week I try to swim 20 lengths of the 25 metre pool. When my chest is bad I can only do 12 lengths. Other things I use at the gym are the Jacuzzi and the steam room, after which I feel really refreshed in my head and chest. I used to do yoga, which seemed to help, and I plan to go back to it when I leave this gym in April.

I am convinced that my breathing has improved since the osteopath — in my twice a month visit — has been using the cranial method. He was actually amazed at how I responded. There have been quite a few times that I could breath so well I forgot to take the asthma puffers. Sometimes the good effects of the treatment may only last for 8 days, but that is 8 days of feeling fantastic, and each time I go I seem to be getting stronger.

Progress with the osteopath is not smooth, because symptoms come and go. The chest seems to be better through June to September. There were times, maybe about eight so far, when I got completely cured, but it did not last more than two weeks. The session with the osteopath is only thirty minutes, so he works on the worst problem only. It can be stiff neck, the swelling in the knee, the chest or the sudden pains I get in the arms.

I should also say that I have a problem with flu injections. I was okay with the first one in 1999, but every injection after that, which is mainly every two years, I have always ended up with flu two months after the injection. The flu injection problem seems to have started along with my sarcoidosis. In future I will not be having any more flu injections.

My treatment by the osteopath is drug free, and my back pain has never returned. I am still taking seretide 250, which does help, although it too has given problems. My consultant suggested that I should take 3 doses, twice a day, not just for the asthma but also because it would be a safe way for me to take steroids to help with the asthma (Seretide contains a small amount of steroids, which is why you must wash your mouth out after use). I did try the dosage he suggested, but after four months I started to get big bruises on my arms and legs. They were not painful, and they were definitely not caused by a knock. We decided that I should go back to 2 doses twice a day, with the option to go up to three doses if I needed it.

The consultant also suggested that I take a salt tablet called Singulair, 10 mg to take every evening. It was excellent in that it dried up the mucus, but after three days I found I got a sharp pain in the knee and head, so now I only take one every so often. The Singulair story is chapter on its own, but as it reveals some of the complexities of treating sarcoidosis, I will dwell on it.

I should say first that one 10 mg tablet per day should be no problem, insofar as on the internet it says you can take at least ten tablets a day. When I first took the Singulair tablet, I made a mistake, and took two tablets instead of one each evening. I almost immediately started to get a problem in my left knee where I had fallen over ten years previously. On the second day of the tablets I had an ache in that knee; next day it was very painful and swollen. At the same time I had a sharp pain on the right side of my head. Of course, I stopped the tablets and told the consultant. He said it should not have caused these problems, and I should continue with them but at the originally suggested dose of one tablet each evening, as it had cleared the wheezing from my chest.

In fact I did not take any more tablets for a few months as I had a problem with that knee for six months. It got very weak. I had to stop exercises and rest it for two weeks, and then I could hardly walk. At the gym they gave me exercises to increase the strength in the knee. The osteopath said that although the knee had a weakness, it was also a possibility that it could be sarcoidosis, because it can affect your joints, and the pain was in the knee joint. Talking about pain in joints and sarcoidosis, a year after sarcoidosis was diagnosed, my middle toe on my left foot went numb; it looked like I had stubbed it. Then I started to get pain in my toes and now I'm getting it in the other foot. I see a chiropodist every two months, which helps, but I now massage my feet with body cream morning and night. If I forget, after I get into bed my feet become painful, and I have to get up and massage them with cream. I do have bunions but they are not painful; it's the toes. However, I try to forget my feet and concentrate on my chest problems.

Unfortunately my osteopath will be leaving the country in the next month but I have already found someone who can do the cranial method and will continue the treatment. Has anyone out there followed a similar treatment to me? I reiterate, I do need to take the seretide, see the osteopath, and go to the gym, leave one out and I get problems.

I can recount one bonus! I am 55 years old and work with a lot of women aged 45 to 60, all of them have had menopause problems, i.e. heat flushing, sweating night and day but I have not had anything like that at all.

Endnotes

1. Seretide is produced by Allen & Hanburys, it's a recent introduction. It comes in 50, 125, 250 and 500 doses. The 250 contains 25 micrograms of salmeterol and 250 micrograms of fluticasone propionate. The one I take is a lilac colour, it has 60 doses, and is in a round plastic container, and to get a dose you pull the lever back, put the container against your mouth and breath in. It is not easy to get from the GP as the

cost is £40 per 60 doses, and at 4 doses a day I need two a month, which works out at £960 a year. There is information about this on the internet and it is for asthma.

David B's Story

About four years ago, the SILA newsletter carried my Patient's Story. Doubtless there will be new members since then, so for this update I will start my story again at the beginning.

I was 30 years old when I first had trouble with stiff joints and muscles. At the same time, I had a problem with a large stone (calculus) in my left submandible saliva duct. I had this removed, but still suffered from swelling of the saliva gland, especially when eating. Also blood tests had shown a very high calcium level in my blood. My doctors were convinced that this was because I ate too many dairy products, and would not believe me when I said that I hardly ever eat them. They said, "Watch your diet and just live with the continuing swelling of the saliva glands; there might be another stone in them, but it won't kill you." I cannot say whether these high calcium levels continued over future years, because the levels were not monitored. I succumbed to the idea that I had the early onset of arthritis in my spine and wrists. In fact my then GP said to me that some people age more quickly than others, and I should get a sedentary job! That was the sum total of input by my GP. I accepted that I was just unlucky!

Many years I suffered with stiffness, tiredness, fatigue and loss of strength. Doing a physical job wasn't easy and still isn't. Eventually, after trying to get GPs interested in my lymph nodes being constantly inflamed, the doctors decided reluctantly to take out my saliva gland. At the same time they also removed two badly fibrosed lymph nodes from my neck. They suspected that this might be cancer. Cancer was ruled out, but it wasn't until I became more ill and could not recover from the operation because the wound was getting really infected and ever more angry, that they thought there might be another problem.

I then became lucky! My regular ear nose and throat (ENT) consultant was on holiday and a younger doctor stood in for him. He recognized in the report the word "sarcoid," mentioned as tissue found in the gland (my consultant said he had never heard of it!).

I was then transferred from Maidstone Hospital to Medway Hospital in Rochester, Kent. Here I saw a lung specialist who assured me that the sarcoidosis disease was slow moving. But within a month, extreme lung shadowing appeared on my x-rays; the doctor was surprised at how quickly it had become life threatening. An emergency biopsy confirmed the presence of granulomas, so heavy steroids were immediately prescribed. I stayed on these for over 4 years. During this period of time I came off them very slowly (see table). Note that it took two years and eight months to step down from 20 mg per day to finally stopping. Despite this cautious approach, there were unpleasant withdrawal symptoms: trembling, shaking, weakness and a feeling of apprehension.

I managed to keep off them for 13 months, but then I requested to go back on them. My hospital doctor thought that a flare up of sarcoidosis might be imminent, although nothing was detected, so he allowed me to start taking them again. After a couple of weeks, he also agreed with my request that I should stop taking them. Another withdrawal bout resumed, and within a couple of weeks I started on steroids again. This time I was on them for just over two months. When I came off them, I once again experienced the feelings of shaking and trembling, accompanied by a feeling of weakness. Doing a physical job and riding in vintage off-road motor cycle trials at weekends probably exacerbated things somewhat. But there was no way I was going to give up and be sedentary. When the

doctor was able to assure me that the sarcoidosis symptoms had disappeared, I decided that I should stop taking steroids for good, and just endure the withdrawal symptoms.

Regular hospital visits were still ongoing just in case the problem reared its ugly head once more. I was finally told that there was no sarcoidosis activity that was detectable and things looked good. I think it was about 2005 that it was declared that I was definitely in remission. But I still visited the hospital for blood tests and x-rays up until July 2007.

By time my doctor was able to sign me off, he said that he had not seen any signs of sarcoidosis in my blood test or x-ray results for about two years after stopping steroids. He did add that he was expecting it to return, because that seems to be the nature of the beast! OK so far!

I can even say that it was a bit sad for me to be finally signed off, as I had been attending his clinic for over ten years, and I felt like part of the team there.

Obviously I still have many after effects and have noticed in other patient's stories that they sometimes refer to the usual back problems. This intrigues me, as I also suffer severe back pain, etc. Oddly enough calcium levels were never discussed with my sarcoidosis doctor. Presumably this was because they were in the normal range during the time I was being examined for sarcoidosis, since a high level of calcium is a moderately common symptom of sarcoidosis. [AF. In the ACCESS study of 215 patients, about 7% of patients were listed as having a calcium problem.]

Perhaps other sarcoidosis sufferers could write in and be more specific about muscle or joint problems that they have to put up with. I have to say I still wonder whether high calcium levels has had a baneful influence on my joints. Since the age of thirty I have always had extremely stiff and painful joints. This mainly includes the back, wrists, ankles, elbows, knees, etc., and in more recent years my neck has very limited movement. My muscles and tendons strain and tear easily.

Back pain has been investigated over several years, but it is difficult to get any doctor really interested in finding out exactly what is amiss. My last visit to hospital was an exception, because an x-ray of my back was taken. I have never had one before, but instead just told that if I could bend and touch my knees and raise my arms above my head, I was in good condition! But after the x-ray, I was told that I had Arthrosic and Spondilosis of the spine. But as my current GP said, I am a determined, positive person, who copes with most things.

Record of steroid treatment

09/07/98	30mg.	20/04/01	2mg daily.0
06/11/98	10mg.	23/07/01	1mg daily.
04/12/98	10mg/5mg alternate days.	19/10/01	1mg alternate days.
30/04/99	20mg daily.	15/12/01	STOP!
14/05/99	10mg daily.	24/01/03	10 mg for 7 days.
30/09/99	10mg/5mg alternate days.	31/01/03	5 mg for 7 days.
18/02/00	10mg Monday & Friday, 5mg other days.	07/02/03	STOP!
01/04/00	5mg daily.	18/04/03	10 mg. Daily (current).
24/10/00	4mg daily.	13/06/03	5mgs.
19/01/01	3mg daily.	30/06/03	STOP!

At times there is a good deal of coping needing to be done! At worst, the back pain is so bad that I have spent a three month period getting better. The first month unable to get off the bed without screaming in pain as my wife gently pulls me up to go to the loo. The second month, I will be able to get about albeit bent over unable to straighten due to the pain. The third month is better, and I know I am on the way back to needing only to be careful and plan every muscular move before I attempt it. I have lost a great deal of flexibility over the last few years, and can only liken it to the feeling that my tendons are shortening and stiffening. My muscles also feel as though they have knots in them, especially the largest muscles.

I do know that I have fibrosed lymph nodes in my chest cavity and other places. My hospital doctor also told me, following a brain scan some years ago, that I had scar tissue in my sinuses. He did not say whether it was attributable to sarcoidosis. I wonder if I have fibrosis type nodules within the muscles, which causes strains and tears more easily.

My skin did thin whilst on steroids but recovered as I came off them. I don't think that the steroids did any real damage, as they were controlled and monitored very closely. I know that taking steroids probably saved my life, so I have nothing but praise for that type of medicine. Also while on the heavier doses you feel like a very healthy superman! Great while it lasts!

As a young boy and man I was considered to be of athletic standard. My heart rate was very low and my lung capacity high. If I relaxed, I could get my heart rate down to 35 beats per minute. It is still very good for a 61-year-old, at 60 beats per minute relaxed. So sarcoidosis hasn't ruined that. But unfortunately the granulomas have ruined my lung capacity, which is below average for my height and weight. I find that my breath is the first thing to disappear when trying to do physical things. I currently walk (march) approximately two and a half miles, five days a week. I would like to jog or run, but I get breathless too soon for that. I am currently on fenofibrate tablets for high cholesterol, which can affect muscles. I was on statins for some time, but they caused a severe muscle reaction when the GP doubled the dose. This lipid problem is not due to diet but is a family trait.

But! Whatever your problems are, never give up, and don't be like me and accept what the doctors say just because you do not want to make a fuss! I wish I had pursued the problem more vigorously at the age of thirty, because I am now sixty one, and could have enjoyed those thirty one years so much more if only I had felt healthier. Old people often say to me that although they look old, they really feel a lot younger. I have always felt exactly the opposite! As a young man I always felt older than I was, and I still do nowadays. No matter how young you are when sarcoidosis strikes, the tiredness, stiffness and general unwell feeling makes you feel old. Unfortunately I cannot remember feeling any different from the age of thirty onwards (except for the steroids). But it doesn't stop me doing what I want to do. I just do things more slowly.

Best Wishes to all sufferers of sarcoidosis, you are not alone. David B.

[AF. Dave's interesting story reflects many aspects of the problems suffered by sarcoidosis patients. For those with access to the internet, there exists a discussion of joint and muscle problems, with 13 different contributors. It is at: <http://sarcoidosis.ning.com/forum/topic/show?id=769148%3ATopic%3A3601>]

CETYL MYRISTOLEATE (CMO) AND CLINICAL TRIALS

by Andrew R.B. Ferguson

It has been suggested that it has not been made sufficiently clear in the SILA newsletters that cetyl myristoleate (the probable active ingredient in a mixture of fatty acids known as CMO) has *not* been subjected to clinical trials for treating sarcoidosis. Thus it is worth emphasizing that not only has cetyl myristoleate not been the subject of clinical trials in treating sarcoidosis, but neither is there a likelihood of such clinical trials (as the phrase is normally understood) being conducted in the near future. To see why that is so, we need to look briefly at the history of the substance.

After Harry Diehl published his 1994 paper in the *Journal of Pharmaceutical Sciences*¹ on using cetyl myristoleate to prevent and cure rats of induced arthritis, he visited several pharmaceutical companies to see if he could interest them in extending the trial to humans; but when they saw that there was nothing in the naturally occurring substance he was using that could be patented, they declined to pursue the matter further.

Despite this set back, some small laboratories, one of them associated with Harry Diehl's family,² produced CMO and started to sell it, admittedly some of them on the back of various ill-founded claims about its efficacy, and with attempts to conceal its origin.

Then, in 1997, Dr Humberto Siemandi carried out an impressive double-blinded, placebo controlled trial, with no less than 205 patients taking a placebo. The trial conformed to all the normal safeguards of probity regarding such trials, and was published in the 163rd edition of the *Townsend Letter for Doctors and Patients*.³ The only significant problem with the trial is the absence of an indication of who financed it, and hence who may have had a vested interest in the results; but the problem of vested interest also exists in the trials carried out by pharmaceutical companies.

The most important outcome of this trial is shown in Statistical Graph 1, which is reproduced in a slightly simplified form on page 15. It shows the key finding of the report, which is that cetyl myristoleate is certainly worthy of further investigation for treating arthritis. The top curve of the graph shows that *with arthritis* further improvement over cetyl myristoleate alone can be achieved by using additional joint supplements, but the main point is the considerable improvement over placebo with CMO intake.

If there were to have been a possibility of patenting something, doubtless drug companies around the world would at this stage have been only too eager to carry out clinical trials; but money, as usual, is the determining factor, so no trials using cetyl myristoleate to treat arthritis have been carried out by pharmaceutical companies or universities.

If this is the case with the collections of diseases that fall under the umbrella of arthritis, which diseases afflict many people, it is unlikely that a trial will be carried out to determine the effect of cetyl myristoleate on the much rarer disease of sarcoidosis. Moreover there are other reasons why a clinical trial of sarcoidosis is difficult.

The course that any case of sarcoidosis is going to take — the prognosis — is very variable. Sometimes there is unexpectedly rapid deterioration, and sometimes improvement occurs without any treatment. There is only one subset of sarcoidosis patients for whom the prognosis is fairly certain, namely those suffering from chronic pulmonary sarcoidosis, who are approaching the stage at which they need to be treated with steroids because otherwise fatal deterioration of lung function is fairly certain to occur. That small subset is suitable as a subject for clinical trials, but being a small subset of those suffering from a fairly rare disease, it will be hard to recruit sufficient patients.

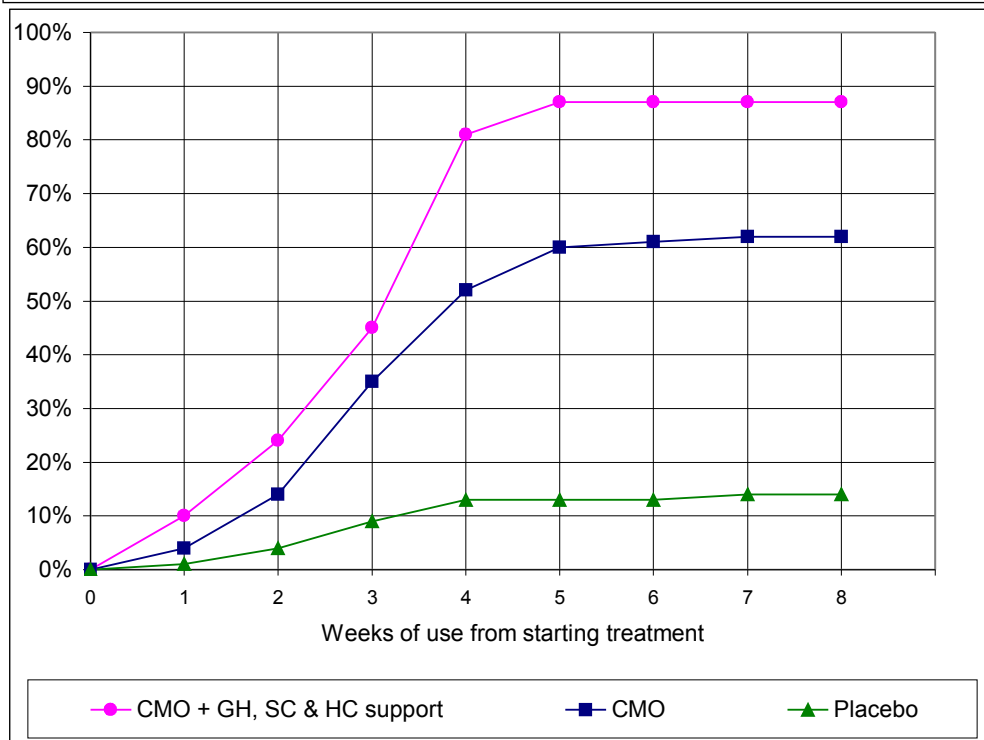
Even if that difficulty could be overcome, there is a further problem of cost on account of the long time that any "cure" of sarcoidosis is likely to take. It is generally agreed that it is likely to be a two or three year project, especially for chronic cases. Also that sort of time span is required to ensure that an apparently promising case is not just a case of a lengthy

remission. Carrying out a clinical trial over three or more years is expensive, and that is yet another reason that such a clinical trial is unlikely to be carried out.

The difficulties of getting clinical trials carried out in respect to sarcoidosis is also illustrated by the small scale trial, of treating skin sarcoidosis with the antibiotics minocycline and doxycycline, carried out by Bachelez et al. in 2001.⁴ They had 10 successes out of 12. Once again drug companies around the world would have been following up this success if they could see a way of making money out of it, but in fact no further trial of using tetracyclines for treating cutaneous sarcoidosis have been carried out.

Overall, therefore, it can be concluded that clinical trials of using cetyl myristoleate to treat sarcoidosis are unlikely to be carried out either on a commercial basis, or probably even by a university. That serves to bring home the level of responsibility that lies with sufferers, because only when they can provide incontrovertible evidence about a non-commercial useful substance is the medical establishment likely to take any interest.

Statistical Graph 1. The percentage of patients, in each of the three groups, who were found to have satisfied the criteria for a response as each week passed. This is a reproduction of the original graph which showed slightly diverging lines appropriate to patient assessment and physician assessment, but they were too close to make it worthwhile to reproduce all six lines. Note that percentages of improvements tended to peak at about 4 weeks, but that was also the end of treatment, begging the question whether continued treatment might have produced a higher percentage of people showing improvement .



AN INTERIM REPORT ON THREE CASES OF CHRONIC SARCOIDOSIS

by Andrew R.B. Ferguson

Sarcoidosis is a difficult disease to study (or maybe it is a collection of diseases under this name), because in nearly all patients what is going to happen (the prognosis) is entirely unpredictable. Sometimes the onset is dramatic, and the symptoms get rapidly worse. Sometimes the onset is not dramatic, but at some later stage there is a rapid deterioration. Sometime it stabilizes of its own accord, and in rare cases it goes away entirely leaving no trace. In all these cases, it is hard to be sure that any medical intervention has been the cause of any improvement which occurs. It should be said that immediate improvement in inflammation with the treatment of steroids occurs so consistently that despite these difficulties the efficacy of steroids *as a short term measure* is not in doubt. Whether steroids affect the long-term outcome is still uncertain, except insofar as that while they are being used they mitigate the tissue damage being done. That of course is important.

There is just one variety of sarcoidosis which does lend itself to study. It is chronic pulmonary (of the lungs) sarcoidosis in which after a considerable period of deteriorating lung function breathing has become so poor that either the patient or the doctor feels that something will have to be done. At this stage the doctor will normally advise the patient that he or she really has no option but to try steroids, because otherwise there will soon be total breathing failure. There is a small window of opportunity, just prior to the doctor giving such advice, when it is possible to try something other than steroids to see if that something can ward off the dreaded moment when steroids become unavoidable. This is a brief interim report of three such cases; first Tim T, who by the end of May 2008 will be in the 58th week of his experiment of this type; second is Rosemary H who at that time will be in the 55th week of her experiment. Lastly I will cover briefly my own experiment. By the end of May, starting from the time I first used cetyl myristoleate (CMO), I will be in the 116th week of the cetyl myristoleate part of the experiment, but actually the experiment started about a year before that with the use of a gel form of *diclofenac* (the substance which is killing vultures in India because it is given to cattle and ingested by them indirectly) sold as Voltarol Emulgel P in the UK. It can be sold without prescription because there is very little active ingredient (it is 1.16% *diclofenac diethylammonium*).

I will assume that the reader has an adequate understanding of the term 'steps per respiration cycle'. In simple terms, it is the number of steps that one can *sustain* — measured on level ground unless specified to the contrary — during each complete breathing cycle, i.e. in and out. To ensure consistency various requirements have to be complied with, but that general description will suffice for present purposes.

Rosemary H

At the start, 16 May 2007, her lung function was at 4 steps per respiration cycle, and her consultant had told her that he thought it inevitable she would have to go onto steroids at her next appointment, due two months after she started the cetyl myristoleate experiment. Within two weeks of starting to apply Myristin Topical Cream,¹ Rosemary's lung function had improved to 6 steps per respiration cycle. She also felt much better with regard to her fatigue problem.

Thus, as with me, she experienced early and dramatic improvement at the point of initial treatment. It is noteworthy that on her next appointment her consultant told her that he thought it unlikely that her improvement was the beginning of a spontaneous recovery, because when such recoveries did occur they did not occur so rapidly.

Her subsequent experiences have been difficult to interpret. One reason for her results being ambiguous, so far, is that when she tried using Myristin softgels, she found that the

¹ . Myristin Topical Cream is the trade name of the cream containing 5% cetyl myristoleate which is sold by EHP Products (www.cetylmyristoleate.com). It costs about \$15 per 50 g.

main effect was gas production and nausea; this is a digestive problem that affects some people. She tried using betain hydrochloride as a digestive enzyme. This solved the digestive problem but the softgels still had no beneficial effect. It has been suggested that a different digestive enzyme, lecithin, might have produced better results, but that remains to be tested. EHP Products sell a product call Myrist-Aid which contains lecithin along with many other things that are chiefly noted for their beneficial effect on arthritis; it still needs to be tested.

On 12 Sept 2007, Rosemary started applying Myristin Topical Cream again, but had only applied a quarter of a pot (with no apparent effect) when she started a cold, and hence the application of the cream was discontinued, as any results would be hard to interpret. Her lung function was at the time 4.5 steps per respiration cycle. On 15 October, she started to apply Myristin Topical Cream again. By time she had completed the application of the cream, on 25 October, lung function was marginally improved to 5 steps per respiration cycle.

There is a reason for the subsequent long period of nil treatment, Rosemary H has always suffered very badly from chest infections, leading to pleurisy during the winter period and the need to use antibiotics. This was so very likely to interfere with any possible effects of cetyl myristoleate, that it was deemed best to wait until the winter period was past. Instead a subsidiary experiment was carried out. Each day she took a capsule, the main ingredients of which are 250 mg of quercetin and 250 mg of vitamin C. Until mid February 2008 she had escaped infection, despite being surrounded by children with their usual colds and coughs; this was looking hopeful on previous experience. However, she then succumbed to a bad cold. Being extremely worried about it going onto her chest, and having a stock of the antibiotic clindamycin to hand, she used it immediately. Whether it was that or the previous use of quercetin that made the difference is impossible to tell, but she recovered in about ten days, and more importantly the cold has not caused the usual chest problems.

Thus at this stage all that can be said about quercetin and vitamin C is that the Quercetin Complex is not entirely effective at preventing colds, although it may have some influence. The subject of Quercetin was covered on pages 7–9 of issue No. 22 of the SILA newsletter.

As a brief aside from Rosemary, I can say that I, too, have been conducting a quercetin experiment, but in my case colds and coughs are not absolutely certain to develop in winter. Nevertheless I do feel that the quercetin and vitamin C capsules (purchased as Solgar's *Quercetin Complex* at about \$30 per 50) may have helped, as although I have often felt myself at the threshold of developing a cold, this last winter I have had no cold since I started using these capsules (I finished taking them at the end of March).

During the cold to which Rosemary succumbed, she reckoned her steps per respiration cycle dropped to 4, but now, 24 May 2008, they are back up at 6. On 13 March 2008, Rosemary saw her consultant and had a chest x-ray and lung function test. The results were encouraging. She has been seeing the consultant every three months. On this occasion, the consultant was able to say that the x-ray showed some improvement, and that the lung function test was not only an improvement on the last test, but the last test had been an improvement on the one before. He thus said he did not need to see her for another six months.

To sum up: because Rosemary H has chest infection problems, she is not an ideal candidate for testing cetyl myristoleate (as was realized at the outset); hopefully more time will allow more definite conclusions. However, she did initially respond to cetyl myristoleate, and she has managed to postpone, although only for about 55 weeks so far, treatment with steroids.

Her lung function has improved by 50%, but unfortunately, except briefly at the start, there has not been a distinct improvement in fatigue. She stresses that it is still bad.

Tim T

Tim T was very keen to avoid going onto steroids, and so had allowed himself to get down to 3.5 steps per respiration cycle. He started to apply Myristin Topical Cream on 24 April 2007. Within two weeks his lung function had improved to 6 steps per respiration cycle.

The next period of using Myristin Topical Cream was 8-22 June 2007. In the first week he improved from 4.5 to 5.5. Lung function then dropped back to 5 steps per respiration cycle, but by 8th July it was again up to 6 steps per respiration cycle. This is a noteworthy improvement of 70% compared to the starting value of 3.5 steps per respiration cycle. Since then he only started using cetyl myristoleate again on 20 April 2008. His lung function has varied somewhat, at one time dipping to 4.5. Perhaps the most useful indication is in the *average* value that has obtained since the initial rise to 6, a couple of weeks after starting treatment. The average value can be estimated roughly at about 5.6 steps per respiration cycle, which is a 60% improvement over the starting value of 3.5.

On 17 February 2008, Tim and I agreed that he should start using some CMO capsules, but unfortunately, at that very moment, he got a waterworks infection requiring the use of antibiotics, so further testing of CMO was postponed. What can be concluded is that there is a clear link between the use of cetyl myristoleate and improvement in lung function, and that up to the end of May 2008, in the 58th week since starting treatment, there has been no need for Tim T to go onto steroids. His current breathing is at about 5.5 steps per respiration cycle, but oil seed rape pollen is preventing accurate measurements just now.

Andrew Ferguson

To fully understand how things have changed since the start of cetyl myristoleate treatment, we need to go back to the year prior to the date of my starting to use cetyl myristoleate (on 18 March 2006). For the preceding year, following a slow decline in lung function, I was using the non-steroidal anti-inflammatory drug (NSAID) Voltarol Emulgel P (*diclofenac diethylammonium*). It was initially consistent in its beneficial effects. The invariable but temporary improvement that it could effect is most easily summed up graphically, as per Figure 1, page 19. The significance of that year of using *diclofenac* is twofold: (a) it confirms that *diclofenac* was only having a temporary effect; (b) it provides a fairly sure indication of what would have happened in this case without treatment of any kind, namely lung function would have continued its slow deterioration, and, following the normal pattern of the disease, most likely continued below 5 steps per respiration cycle.

On starting the application of CMO cream, on 18 March 2006 (I was using a CMO Distribution Center product at the time — a firm that has now disappeared), my lung function improved from 5 steps per respiration cycle to 7 within a week, but there was no further progress during the next week of using the cream; lung function then dropped back to 5 steps per respiration cycle within a week of ceasing to apply it.

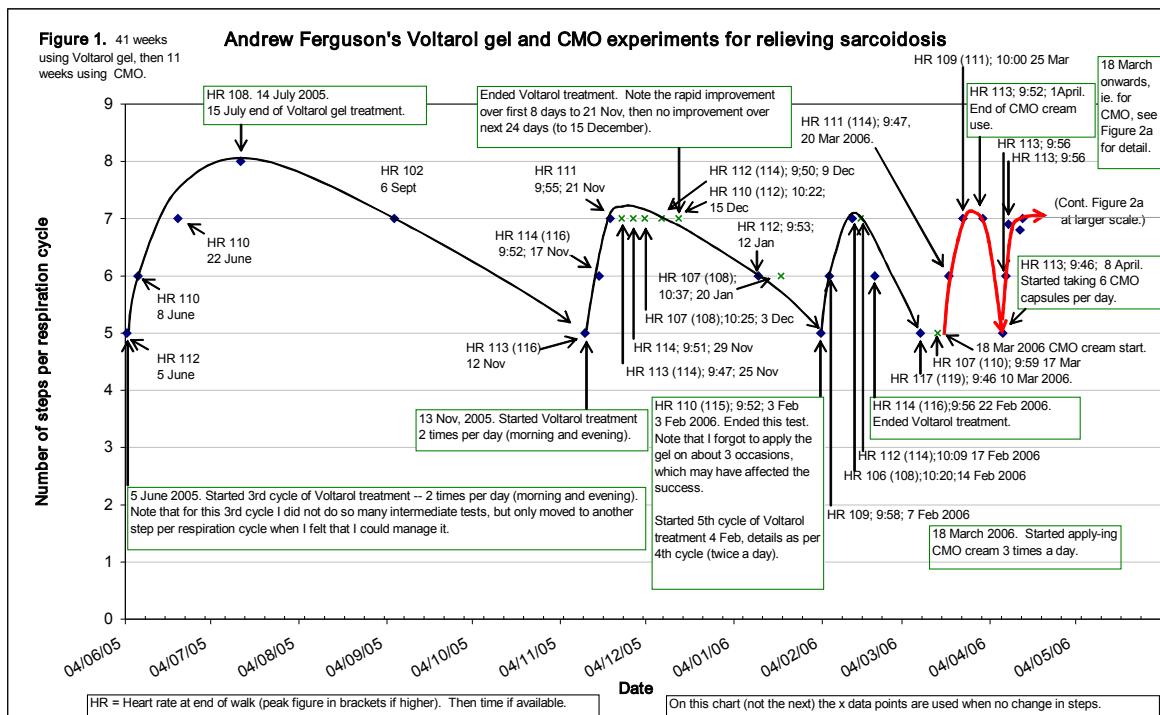
On 8 April 2006, I started using CMO capsules (from the same now defunct firm) and within *2 days* lung function had improved from 5 to 6.9 steps per respiration cycle. Moreover, on this occasion, the lung function did not undergo the deterioration back to 5 steps per respiration cycle that had been occurring so consistently previously. In fact, *during the nearly two years* following that rise to 6.9 steps per respiration cycle, lung function on level ground never dropped below 6.6 steps per respiration cycle.

On level ground, the *average* was 8.8, a 75% improvement, and on the 1:20 upslope (a rather less accurate measurement), the *average* was 7.1, a 110% improvement. Such improvements are subjectively spectacular, removing as they do any imminent threat of the need to use steroids, although it should be mentioned that neither of these measurements is very close to normal lung function. Both the 8.8 steps per respiration cycle on the level, and the 7.1 on the upslope, represent about 70% of a probable normal.

The sudden improvements mentioned above, which occurred when I started using cetyl myristoleate, are hard to explain except on the basis that the cetyl myristoleate was the causative factor, but there is an obvious need to look for further confirmation of effectiveness during the subsequent use of cetyl myristoleate. Unfortunately the effect of subsequent applications has been far less clear cut. There is a plausible explanation for this. Cetyl myristoleate may be both an anti-inflammatory and a immuno-modulator. When inflammation is extensive, rapid improvement will be apparent, but improvement due to immuno-modulator effects is likely to be slower.

The main focus in reporting this trial has always been on lung function, since it is a measurable quantity; but an erratic overwhelming feeling of fatigue and persistent cough was always equally important during the time that sarcoidosis was rampant. Remarkably, the fatigue went away within a week of starting using CMO cream, right back in March 2006. The cough improved 80% in that same week but took about 40 weeks before it had disappeared altogether. In fact the cough has returned over recent months in an attenuated form. It is hard thing to rate, but I roughly assess it as being 80% improved. I still rate the improvement in fatigue as 100%, but with great uncertainty, as that too is hard to assess. The 100% rating is mainly because when I feel tired nowadays, it is *not in the same way* that I used to feel totally exhausted, with my head 'full of treacle', so I put present problems down to 'normal' tiredness rather than a return of the 'fatigue' symptom so typical of sarcoidosis, and so frequently bemoaned by sarcoidosis sufferers.

The final symptom is dry eyes. I reckon this has been almost 75% better for most of the period of the cetyl myristoleate trial, now extending over 116 weeks (in terms of the amount of Hypromellose I have to use each night – virtually no problem by day).



A significant amount of research on sarcoidosis is being done at Johns Hopkins University (a teaching hospital in the USA). As mentioned at the end, the doctors there are kept so busy treating sarcoidosis patients that they do not have time to do proper research and publish research papers. Fortunately Wayne Hunter, himself a longstanding sarcoidosis patient, has been able to keep tabs on what is going on there. Below are some notes that he made when attending a presentation given by Dr Edward Chen. See Wayne's caveat at the end regarding accuracy. I have liberally interspersed his notes with further explanatory notes. Many of my notes are derived from reponses obtained from Wayne when I put further questions to him after reading his notes. Wayne Hunter is a frequent contributor to the Sarcoidosis Network. His work is with the technical equipment used by the medical profession, so he has thereby gained a good background knowledge of medical matters. Andrew Ferguson.

Notes taken by Wayne Hunter from a presentation on "Sarcoidosis, Clinical Concepts and Treatment" by Dr. Edward Chen of Johns Hopkins University

(with explanatory annotations by Andrew Ferguson [AF. ...] stemming mainly from further enquiries put to Wayne Hunter about his notes.)

Sarcoidosis is very similar to Common Variable Immunodeficiency (CVI) and Juvenile Rheumatoid Arthritis (JRA).

Sarcoidosis is not easy to diagnose because it is diagnosed by exclusion of other diseases, not by direct methods.

Sarcoidosis is a complex disease. The different types of the disease often require different treatment protocols and dosages. The problem is to not over-treat the patient or create a treatment that is worse than the disease. The main reason for over-treatment is due to the fact that the macrophages [AF. Immune cells] have such a long lifetime in the body. Because of this lifetime being from months to years, the response time to treatment is months to years, not days to weeks. When physicians do not see a response in a few weeks, they often increase the dose, even though the dose may have been correct.

Johns Hopkins University doctors do not treat many patients with Optical Sarc. They refer these cases to an Ophthalmologist. [AF. Note that there is a highly erudite paper by Dr Andrew A Dahl, Assistant Professor of Surgery (Ophthalmology), titled simply *Sarcoidosis*, which is available on the net.^[1]]

Many sarcoidosis patients have sleep disorders either caused by breathing problems or other issues arising from sarcoidosis. Often it is the sleep disorders, not just another aspect of sarcoidosis symptoms, that results in the fatigue that many patients complain about. [AF. Maybe often, but certainly not always. As many sufferers will testify, sarcoidosis fatigue is often different in kind from normal fatigue from lack of sleep.] Since the body is also creating excessive amounts of lymphatic fluid, this contributes to the fatigue as well. Fighting the pain associated with the disease also increases fatigue.

Sarcoidosis can affect any area of the body that has lymphatic fluid. The most common affected areas are:

1. Lungs; 2. Eyes; 3. Lymph; 4. Skin

Sarcoidosis may possibly be triggered by an infection or other environmental substance, but, it is *not* an active infection.

Agents which are suspected of commonly triggering Sarcoidosis are:

INFECTIOUS	NONINFECTIOUS
Micobacteria (Tuberculous, Nontuberculous, and Cell Wall Deficient)	Dusts (Clay, Talc, Pollen, Pine)
Bacteria (many types)	Metals (Beryllium, Zirconium, Aluminum)
Fungi	Chemicals (Silicon, Asbestos, CFCs)
Viruses	

When performing a standard gel exposure test, the S6 antibodies are recognized to not match the response of a normal person. More specifically, this is a DNA test with an apparent defect in the S6 antibodies area of the DNA string. Unfortunately, the researchers have not narrowed it down to the exact genetic defect. The S6 area encompasses about 4-5 million DNA combinations.

Studies are continuing on the information and findings of micobacterial proteins within the granulomas.

These studies are not from a large enough group of patients to be clinically significant. The study needs to have either ACCESS or SAGA studies performed to validate the tendency of a large portion of sarcoidosis patients to have micobacteria proteins within the granulomas. [AF. To my knowledge, there is good evidence for micobacteria fragments of various kinds being found in a high proportion of sarcoidosis patients. The question is whether these are the trigger, or in any way causative of the symptoms. When I made that comment, Wayne explained: “The issue is that proteins within the granuloma that are not within the macrocell center of the granuloma have not been proven to be a trigger. Only materials within the macrocell are known trigger substances as this is the material to which the macrophages are responding to protect the body. Other substances within the granuloma, but not within the macrocell, are things that the macrophages have attacked, but are not the original trigger”]

Some things that appear to be *negative* risks for sarcoidosis include Smoking Tobacco, Second hand smoke, cats, and animal dust. However, most of these have other health risks that may preclude them from future study proposals. [AF. There is some logic in this finding, namely that any body which is used to dealing with allergens would behave differently when it encounters an allergen that would in many people be a sarcoidosis trigger.] There is also a theory that if you overstress the system to the point that it saturates, the response becomes less. This is the way that allergy shots work on the immune system. But, again, not enough data to put this forward as a theory. As more of the research tends to move toward similarities between allergy and Sarc, this may prove to be the reason. But, for now, it is only an observation.

One of the major findings of drops in PFT results [AF. Pulmonary Function Test] is the stiffening of the lung structure. This leads to lost elasticity and volume. [AF. Loss of vital lung capacity is indeed one of the most obvious and most easily measured aspects of pulmonary (lung) sarcoidosis. However, medical sources in the UK correctly, in my

opinion, identify a large portion of the loss of vital lung capacity to lack of transpiration of oxygen through the lung walls.]

Sarcoidosis can also affect the lining of the airways and bronchia. This can create problems for separating out the diagnosis as sarcoidosis rather than asthma.

There is significant data to show that sarcoidosis patients can continue to have increased lung function beyond the first year of treatment. This is the main reason to continue treatment with medications [AF. Wayne has indicated to me that by extending treatment beyond when remission appears to have occurred, the chance of a relapse is reduced.].

Sarcoidosis can result in Pulmonary Hypertension [AF. Also called Pulmonary Arterial Hypertension (PAH); this refers to continuously high blood pressure in the pulmonary artery. The average blood pressure in a normal pulmonary artery is about 14 mm of mercury when the person is resting. In PAH, the average is usually greater than 25 mmHg. PAH is a serious condition for which there are treatments but no cure. Treatment benefits many patients.] Treatment is usually by use of Prednisone, but vasodilators also can work. It may develop into sleep apnea. [AF. Sleep disturbed by breathing problems.]

Cutaneous sarcoidosis [AF. Skin sarcoidosis] includes Erythema Nodosum and Lupus Pernio. Treatment most often leaves dents and scars. [AF. These notes were taken prior to the study by Bachelez et al., in which 10 out of 12 patients were apparently cured of skin sarcoidosis by the use of the antibiotics minocycline and doxycycline. People with access to the web can read the entire well-written paper.¹²³

Parotid (the largest salivary gland), other Salivary glands, Sinus, Larynx, and Tear Ducts can also be affected by sarc.

Neurological sarc has 3 different types. These can include lesions (the permanent damage state), brain sarc (an early stage), or spinal cord involvement that can cause nerve problems. Neurological sarc requires long term treatment, described as more than 5 years.

Neurological sarc is usually treated with both Prednisone and a 2nd tier medication [AF. i.e a non-steroid medication.] . The trick is to determine which 2nd tier medication will work. [AF. See further discussion later.]

Neurological sarc can cause Cranial Palsy [AF. Cranial Palsy is a loss of muscle control in the head and face area. A good example of Cranial Palsy is the drooping mouth that is common after a stroke.], Ear Pain, and Tinnitus. These symptoms often come and go. It can also cause Peripheral Neuropathy, or tingling in the arms, legs, hands, and feet. Peripheral Neuropathy does not respond well to therapy.

Cardio sarcoidosis is more common than the diagnosis rate suggests. The diagnosed rate of Cardio Sarcoidosis is between 2-7% of sarcoidosis patients. When performing autopsies on sarcoidosis patients, 20-50% of them have evidence of Cardio Sarcoidosis.

Cardiomyopathy can also be caused by sarcoidosis [AF. **Cardiomyopathy**, which literally means "heart muscle disease", is the deterioration of the function of the myocardium (i.e.,

the actual heart muscle) for any reason. People with cardiomyopathy are often at risk of arrhythmia (irregular heart beat), or sudden cardiac death or both.]. Diagnosis can be made by performing indirect scans.

Cardiac MRI [AF. Magnetic Resonance Imaging.] is a growing technique for diagnosis of sarcoidosis induced Cardiomyopathy. Arrhythmias caused by Cardio Sarcoidosis are usually treated by insertion of a defibrillator [AF. Another name for this is a “pace maker”]. There is some research into the possible use of immuno-suppressants as the new treatment for this type of Sarcoidosis. [AF. Although prednisone is a low level immuno-suppressant, it is not normally classified as one, but rather as an anti-inflammatory.]

DIAGNOSIS:

The most common secondary methods of diagnosis are ECG [AF. Electro Cardio Gram], x-ray, urine tests [AF. Urine tests are mainly used for looking for high levels of calcium and magnesium in the urine to determine if the body is disposing of calcium or magnesium through the kidneys leading to kidney disorders. It is also used to look for other chemicals in the urine that would rule out sarc.], blood tests [AF. Most, but by no means all, sarc patients have high ACE (angiotensin converting enzyme) levels indicating elevated inflammation associated with active sarcoidosis. One can also look at Immunoglobulin levels to rule out other immune disorder triggers.], PFT [AF. Pulmonary Function Test], and CT [AF. Computer Tomography. This is superior to a normal xray. My radiologist seemed confident that it was sarcoidosis when he looked at my CT scan. Unfortunately it involves higher doses of x-rays so is used sparingly.]

Newer tests are Gallium or PET scans [AF. PET is Positron Electron Tomography.] No single test is capable of diagnosing sarcoidosis because it can only be sarcoidosis if it is *not* something that can be categorized under a known disease or disorder. The PET scans are looking for the amount of uptake of a radio nucleotide into an organ or body area. This can indicate cancer instead of sarc. Again, the tests are to rule out anything else possible, to allow for the diagnosis of sarcoidosis by exclusion of every possible known disorder or disease. One new technique that is not yet proven is MRI with Gadolinium.

The only sure diagnosis is a biopsy with screening tests for infection or malignancy. [AF. i.e. biopsy of the granuloma needs to be characteristic of sarcoidosis granulomas with no sign of infection or malignancy. In practice, some doctors think that in some cases symptoms are so characteristic of sarcoidosis that a biopsy is not essential.]

Testing for sarcoidosis in Skin, Liver, Muscles, and Peripheral Limbs results in a lower incidence of positive identification. It is harder to obtain good samples and to determine the location to biopsy to provide evidence of the disease.

The disease does not have a single diagnostic technique for all forms. There are specific tests and appropriate responses for treatment based upon the organ or area of the body that is affected.

NEURO SARC: Neuro Sarc can be best diagnosed using MRI with contrast [AF. The MRI with contrast will determine whether the nerve is damaged, continuously firing,

causing the pain, or referred pain. Damage to the nerve, unless from excessive fluidic pressure from sarc, is not sarc but neuro-damage. The amount of nerve activity can be studied by the use of MRI with contrast. Sarc will cause excessive nerve firing to occur due to the pressure in the area being interpreted by the nerves as pain or injury, or granulomas within the nerve casing.], Nerve Conduction Study, and Lumbar puncture. [AF. The lumbar puncture takes spinal fluid for analysis. This is the explanation of its use given by Wayne: “If the fluid contains non-caseating granulomas and you have Sarc, it indicates Sarc in the nervous system. If it is in the fluid around the nerves, it is also within the nerve casing. Hence, it is neuro-Sarc.”] Neuro can also cause Sleep Apnea and Fatigue. [AF. However, from the experience of members of the Sarcoidosis Network it would seem that every form of sarc usually causes sleep problems and fatigue.]

CARDIO SARC: Cardio Sarc has many of the same requirements as Neuro. Other tests including stress tests can be used to determine Cardio. The stress test is the test that is done to determine whether damage has occurred to the heart after a heart attack. The patient is put on a treadmill with heart monitoring equipment attached and the speed and incline of the treadmill increased to determine the rate of heart activity with increased stress on the body. [AF. This was one of the many tests I had. I had to breathe unusually fast, and this was noted, but that seems to be all that they found.]

TREATMENT

Treatment of Sarcoidosis is performed by the use of 1st and 2nd tier medications. First tier medications include steroids, the most common being Prednisone [AF. The primary effect of which is anti-inflammatory although it is also a low level immuno-depressant.]. Second tier medications include antibiotics, cell growth blockers, and other nonsteroidal medications [AF. These other nonsteroidal medications include Anaprox, Naproxen, Aspirin, Ibuprofen and Diclofenac. What is used depends on the level of inflammatory control required for *your pain* level and what works for you. Note that Dr Moller covered a substantial part of the whole range of 2nd tier medications in his paper *Treatment of sarcoidosis – from a basic science point of view*, a four page condensation of which is available on the Sarcoidosis Network as the Discussion **Beyond corticosteroids**.^{3}]

Cardio and Neuro Sarc do not respond well to 2nd tier medications, e.g. methotrexate and antibiotics, when used alone. Both types respond best to treatment with both steroids and 2nd tier medications. The problem is determining which 2nd tier medication provides the best response.

[AF. It is indeed. I recall that a presentation to the American College of Chest Physicians^{4} reported that using methotrexate together with steroids appeared to be of no benefit over using steroids alone. However I have subsequently learnt that methotrexate may allow a lower dose of steroids, which is definitely beneficial. As Wayne continuously emphasizes, every patient is an individual experiment. On another point, Wayne observes that since nerves and cardio muscles do not have good regenerative capabilities, it is necessary to control the inflammation first, then treat the disease. Steroids have both an

anti-inflammatory and a low level immuno-suppressant action, but are generally agreed not to be actually curing the sarcoidosis.]

Treatment of sarc is not quick. Sarcoidosis patients generally do not respond quickly to medications or treatments. This leads to over-treatment of many patients.

Treatment time varies with each patient. However, the doctors at Johns Hopkins have found that treatment requires from ½ to 2 months *minimum* to determine if a treatment regime is working. Most doctors do not have the patience to wait long enough to determine whether a treatment is working before changing treatment methods or dose rates.

When treating sarcoidosis, once a response and treatment medication is determined, minimum treatment time is **1 YEAR!** Again, sarc is usually not a fast disease and it does not respond quickly. It takes more time and patience than other diseases to treat effectively.

When treating for sarc with a mix of medications for tough forms like Neuro and Cardio, treatment should be to start with Prednisone *plus* a 2nd tier medication like Plaquenil, Minocycline, Thalidomide, Methotrexate, Remicade, etc. Since there are approximately 20 different 2nd tier medications, this can be a *long experiment*.

(20 medications x 2 months per medication = 40 months)

Some new 2nd tier medications, like Infliximab (an anti-TNFalpha medication) are showing promise for future treatment.

When treating Sarcoidosis, it is important to determine the worst body system affected, and treat this first.

To get the body to calm down and stay in remission, treatment must continue for a significant period beyond the point of remission. If not, the body tends to go into rebound. Using the half life theory, once remission is accomplished, treatment should continue for 2 more half lives of the particular macrophage being targeted. Since each different macrophage in the body has a different half life, the treatment time is variable. As a general rule minimum treatment is 2 to 5 years.^{5}

Forms of Sarcoidosis that are categorized as Chronic with active insidious onset, and extensive interaction are Pulmonary, Lupus Pernio, Sinusitis, and Neuro/Cardio. [AF. Active insidious onset refers to a slow, unexpected, and unexplained increase of the disease in other areas of the body.]

Sarcoidosis can be characterized by both hypocalcaemia and hypercalcaemia. [AF. Hypocalcaemia is low calcium level in the blood and hypercalcaemia is a high level.] Either of these conditions can affect the liver and kidneys. The usual problem with hypocalcaemia is that the magnesium levels elevate in the body. Magnesium can cause the same problem in the liver and kidneys as calcium.

Treatment of Sarcoidosis is mainly to prevent the formation of fibrous tissue (scarring).

TAPERING OFF PREDNISONE:

Tapering off Prednisone is a long term process. Since the body and immune system of a Sarcoidosis patient responds much slower than a normal patient, it requires a significantly longer period of time to taper off than other diseases.

The recommended dose taper rate used for Sarcoidosis patients at Johns Hopkins is:

INITIAL DOSE RATE DOSE	TAPER	TIME
More than 30 mg per day	10 mg	Every 2 weeks
30 mg – 20 mg	5 mg	Every 2 weeks
20 mg – 10 mg	2.5 mg	Every 1-2 MONTHS
At 10 mg	0	Starting dose less than 30 mg – 6 Months Starting dose more than 35 mg – 12-24 Months
10 mg – 0 mg	2.5 mg	Every 2-4 months

[AF. It is perhaps helpful to have an overview example of that. Suppose 40 mg per day was the starting dose, then the time to get to zero would be between 102 and 198 weeks, or in round terms 2 to 4 years.]

NEURO treatment: Start treatment with a dose rate of 1 mg Prednisone per kg of patient weight *plus* a 2nd tier agent. Johns Hopkins University has about a 30%-50% hit rate on selection of the 2nd tier agent on first attempt. They are attempting to find other researchers to do more studies about how to be able to select a 2nd tier agent. After 2-5 months at above dose, start a SLOW taper off the Prednisone. The goal here is to get the steroid down to the point that it is only acting as an anti-inflammatory, not an immunosuppressant. That way, the physician can better understand the effect of the 2nd tier medication in treating the sarcoidosis. The goal is to get below 20 mg as fast as possible without stressing the body too much, and get below 10 mg per day to minimize the immunosuppressant effect of the steroid.

CARDIO: Same as Neuro treatment.

MUCOCUTANEOUS: Use a dose of approximately ½ mg per kg of patient weight *plus* a 2nd tier agent. Taper the same as Neuro.

Johns Hopkins University is attempting to hire 2 more sarcoidosis specialists at this time. Because they are so short of staff, they are not actively doing any research projects. Again, these are my notes from the meeting. They are not Dr. Chen's presentation. He takes no responsibility for anything I said. I think I got most of them right, but, some of the things were presented fairly quickly.

Wayne Hunter

Notes

1. The paper by Andrew Dahl, Assistant Professor of Surgery (Ophthalmology), titled simply *Sarcoidosis* is available at <http://www.emedicine.com/oph/topic451.htm>
2. The paper by Bachelez et al, recording a 12 person clinical trial using tetracyclines on skin sarcoidosis is available on net at <http://archderm.ama-assn.org/cgi/content/abstract/137/1/69>
3. The Discussion **Beyond corticosteroids** is available to members of the Sarcoidosis Network at <http://sarcoidosis.ning.com/forum/topic/show?id=769148:Topic:20093>, and it contains, as an attachment to the first post, a condensation of Dr Moller's *Treatment of sarcoidosis – from a basic science point of view*?
4. This short report, mainly a discussion about the use of prednisone for treating sarcoidosis, is to be found at <http://tinyurl.com/2uczvx> ("Improves Symptoms but not Lung Function in Sarcoidosis").
5. Treatment was shorter than this in the trial by Bachelez et al. They reported that, "The mean time to reach maximal response to cutaneous lesions from the date of onset of minocycline treatment was 3.2 months (median 3 months; range, 1-6 months); ..." But note that the treatment (with minocycline at 200 mg/day) was for a median duration of 12 months.

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

The Secretary, SILA
c/o The Chest Clinic Office
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 web-site.

SILA AGM will take place on Thursday October 2nd, 2008 in the Boardroom of King's College Hospital, Denmark Hill, London SE5 at 7pm. All fully paid up members can vote at the meeting. Afterwards there will be the usual support meeting.

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. Mary Walters attended the meeting of EPOS (European Organisation for Sarcoidosis and other Granulomatous Diseases) in Luxemburg in May 2008.

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

Affordable Family Holidays At popular holiday sites for all families with special needs: The Scout Holiday Homes Trust, Gilwell park, Chingford, London E4 7QW Telephone 020 8433 7290 (24 hours); email lynda.peters@scout.org.uk, www.scoutbase.org.hq/holhomes

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.

- 1 . Diehl H.W., May E.L. 1994. Cetyl myristoleate isolated from Swiss albino mice: an apparent protective agent against adjuvant arthritis in rats *Journal of Pharmaceutical Sciences*. 1994 Mar, 83:3,.296-99..
- 2 . At least one person in the firm EHP Products Inc. (www.cetylmyristoleate.com) is a blood relation of the person who discovered cetyl myristoleate, Harry Diehl.
- 3 . Siemandi, H. 1997. The Effect of cis-9-Cetyl Myristoleate (CMO) and Adjunctive Therapy on Arthritis and Auto-Immune Disease, *Townsend Letter for Doctors and Patients*, Issue #169, pp. 58-63
- 4 . Bachelez, H., Senet, P., Cadranel, J., Kaoukhov, A., Dubentret, L. 2001. The Use of Tetracyclines for the Treatment of Sarcoidosis. *Arch Dermatol* Vol. 137, Jan 2001, pp.69-73.