



S.I.L.A. NEWSLETTER 25 SUMMER/AUTUMN 2009



Dear SILA Supporter,

I have always begun '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.

Supporters have formed The Sarcoidosis Support Community and not all are members of SILA, but have been working hard to raise awareness of sarcoidosis. SSC has got up a Downing Street Petition to present on 4th June, 2009. This petition got under way too late to feature in the last SILA newsletter. The petition has brought newspaper coverage and local broadcasts and cabinet ministers and MPs are now involved. SSC has organised local support meetings for now and in the future. All this information can be found on SILA's web-site and further information from the organisers' email: UKsarcoidosis@live.co.uk. More news about SSC will be in the newsletter after this one.

Steven of Corby was mentioned in the last newsletter as having been diagnosed with sarcoidosis two years ago and as having been severely deaf from birth. Steven would have liked to hear of a SILA Support Group in set up in Northampton, near the Town Centre, if possible. Steven cannot drive and relies on public transport and he needs BSL (British Sign Language) interpreters at all meetings. I contacted Steven who tells me that he has had no response from the mention in the newsletter, and would still like to get emails from hearing or deaf sarcoidosis patients. To email Steven: cooltiger@ntlworld.com.

SILA's membership of LTCA (Long-term Conditions Alliance) was mentioned in Newsletters 23 and 24. LTCA has merged and is now National Voices www.nationalvoices.org.uk Tel. 0207 813 3644. I attended the National Voices Event: Prescription Charges for People Living with Long-term Conditions, held at The Royal National Hotel, Bedford Way, London on 4th March, 2009. A busy day of talks and discussions included: Introduction to Prescription Charges Review: A List of Medical Exemptions? and A Definition of Long-term conditions.

I have been sent news of an interesting development about weather forecasts being used to help patients with respiratory diseases, in Nottinghamshire. Cold weather can be bad news for all patients with respiratory problems. If this pilot scheme is successful it will go countrywide. Watch this space or contact NHS Direct for more information.

I hope that all will continue to send in their Patient's Stories for the next newsletters and I hope everyone will enjoy the coming days and there will be better health prospects to come.

As usual all who renew their subscriptions to SILA so promptly and include donations are much appreciated.

Heather Walker, Editor, email heather@silas.org.uk

Andrew Ferguson, Assistant Editor.



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This edition of SILA Newsletter covers several quite different possible palliatives for treating sarcoidosis, starting with Deb's success with the Marshall Protocol; going on to a modest success in 3 cases treated with cetyl myristoleate (CMO); a striking success with three cases of treatment with pentoxifylline and doxycycline; and a rather shaky report covering a 10-year study of methotrexate. It is perhaps a wise precaution to say that while the facts contained in these accounts are as accurate as we could make them, any conclusions that we draw from them are our personal opinions, made without any special knowledge, so it is the responsibility of every reader to draw their own conclusions.

An extra warning may be appropriate with regard to Deb's account of her success with the Marshall Protocol (MP). There are others who have had similar success with the MP, but there is a fundamental problem with it, namely that it is impossible to continue to follow and report on the people who drop out, and many without doubt do. Since it involves taking a variety of antibiotics over a long period of time, it is not something to be undertaken lightly, so what is needed is a realistic idea of the proportion of people who respond well, and those who respond particularly badly (i.e. more than it being just ineffective). I have tried to find someone belonging to the "particularly badly" category, but none have proved articulate enough to provide us with a useful story.

On page 6, Heather Walker reviews a book *A Patient's Voice*, which has this long introductory subtitle: "Inspiring and practical advice about living with Chronic Health Conditions, such as cancer and Sarcoidosis. And achieving Positive results regarding all your Health Care needs — All written from a Patient's Perspective and personal experience." The author is Gilbert Barr Junior. I expect that many people will find the book helpful, for there is no doubt that many people who join our Social Network which Henry Shelford set up, the Sarcoidosis Support Community at <http://sarcoidosis.ning.com>, find solace in discovering other people who are suffering similar problems from their own. In my opinion there is scope for the Social Network to do much more. Indeed, I think that it as likely that a sarcoidosis patient will, by careful observation and record keeping, discover one or more very helpful palliatives to sarcoidosis, as that there will be a break through by medical researchers. It is apparent that sarcoidosis takes so many different forms, and has such uncertain prognosis, that investigating it along normal scientific lines would be hard even if it were to be such a prevalent disease that immense effort was devoted to it, with no expense spared.

Whether you agree with those surmises or not, we hope that if you have access to the internet you will join the Sarcoidosis Support Community, and enhance it by divulging your own experiences, and reporting on your own trials. It only remains for us to hope that all SILA members will find something of use in the varied stories and reports which Heather and I have gathered together for this issue.

Andrew Ferguson

Deb's Story
(Deb is from Michigan, USA)

Growing up it seemed that I showed mild allergies to the normal triggers but I didn't realize until I became older that "something" was affecting me both physically and neurologically, having to do with my immune system.

I married at 19 and moved from a small city to the country. We gutted our large 80 year old farmhouse without the use of respirators. At this time my "allergies" seemed to be getting worse. I had many chest related problems that year. I was diagnosed with asthma and put on steroid inhalers. We also heated our large farmhouse with a woodstove, which I've recently learned can be a real lung irritant to Sarc, from both the smoke and mold on any wood stored indoors. I suffered bouts of chronic bronchitis and constant coughing. When I caught a cold it would never clear on its own but would linger and end up in my chest, always needing antibiotics to resolve. This seemed to relieve itself years later when we moved into a home with central heating. I often wondered why others got colds and they just went away, unlike mine.

In my childbearing years, I delivered three lovely children via caesarean-section. After my last child was born I started having some very severe neck pain. At the time I chalked it up to the epidural that I'd been given. But it was the kind of neck pain that would bring me to tears. This pain has literally been with me every day of my adult life, despite massage from loving family hands, and chiropractic treatment. Note I have since learned, through my research, that avoiding surgery when possible is advisable for those with sarcoidosis.

In 1990, I had yet another surgery. That fall my husband and I bought a 100 year old Victorian home. I had always wanted to restore a vintage home, but I was in for a surprise! We moved into the house and started once again tearing out walls, and once again dust and mold!

At this point my body was at a breaking point, I had just turned 35 years old. My first flare, as I now know I was in a Sarc flare, began with a sensation that I was losing my balance. Soon both ears were fully plugged; I had lost spatial grounding (felt like I was detached from the earth), and suffered leg tremors; loss of partial vision in my left eye; neck pain intensified; facial edema; head felt swollen; intense fatigue; memory loss; brain fog; terrible concentration; body edema; leg tremors; and low grade fever would not go away. At this stage I could only connect the problems with our move to a new house and the mold exposure that seems prevalent in older homes. We soon moved out of our house as I felt I needed to see if it would relieve my symptoms to get away from all of the dust and renovations and chemicals. Although I felt a slight improvement, my body was still in chaos.

We went to doctor after doctor, lab results coming back were iron at 5, low platelets, white blood count high and all these neuro symptoms that no one could put a finger on; other than to have one internist tell me to see a shrink! Yet the existence of a problem was visible just looking at my eyes. My ears were fully plugged 24/7 for the next three years and throbbed. I lived with constant dizziness. My eyes were extremely sensitive to artificial lights and bright lights. Any chemical smell would put me into a spin. I tended to ascribe all these problems to allergies. This appeared to be confirmed when I tried allergy shots and found out I was highly sensitive to mold. Any attempt to take mold shots made me extremely ill. I found a well known allergist named Dr. Derrick. He was the first

compassionate doctor that I had dealt with. He felt I was dealing with Chronic Fatigue Syndrome and worked to support the immune system. He was close but not quite on to a diagnosis.

At this point, I just struggled to get through each day. At 40, an aunt gave me a massage certificate for my birthday and I started going regularly for massage. Within the next two years I started feeling some small relief from these horrible debilitating symptoms. By 1997, I was beginning to stay up again until 11 pm at night. It was a sign that I had “recovered,” or so I thought! Life seemed fairly good again, although I still had to battle fatigue. Exercise induced fatigue and pressure in my chest. I never could quite understand how my husband felt so good after exercise, when it drained me.

We had returned from a ten day Caribbean cruise when I noticed that once again I was starting to feel more “run down” than usual. This time I ascribed it to three teenagers, and a demanding job. But I still felt “tired” all the time.

In the fall of 2006, I was exposed to my husband’s elderly uncle, who had pneumonia and later MRSA. Two weeks later it was my 50th birthday and I was feeling ill with extreme chest pressure. I thought it might be bronchitis again because my chest felt so full. My doc put me on an antibiotic and sent me home. This repeated itself three times using three more antibiotics. Then I asked for a chest x-ray. It turned out to be pneumonia.

The lung problem having been diagnosed as pneumonia, my own GP missed the Sarcoidosis on my x-rays, which was later noted by my specialist. On Christmas day 2006, I had such pain under my ribs and pressure in my chest that I thought I was having a heart attack. I took myself into ER on that night of the 26th and I bless the ER doc who sent me for a CAT (computer assisted tomography) scan which showed enlarged lymph nodes. [AF. CAT scans are superior to x-rays but give a higher dose of radiation so doctors are a bit careful in asking for them to be done.]

My GP thought the problems were left over from pneumonia and that I needed to wait a few weeks, but by that time head pain in the back of my head had returned. Since at this point there was concern about my heart, I was sent the next week for a heart catheter. The good news was that my arteries were clear. It was Sarc in my heart muscle giving me these symptoms of no oxygen and chest pain. Blood sedimentation rate was at 48. ACE (angiotensin converting enzyme) had come back to normal, which shows that the ACE test is not always useful with every Sarcoidosis patient.

At this point I finally felt my GP was dealing with something unfamiliar and asked to see a lung specialist. As is not unusual, there was uncertainty whether it was lymphoma, but when the biopsy came back, sarcoidosis was confirmed. At this point I was spending most of my time resting and my specialist decided to put me on steroids. My problems exacerbated with the steroids. My blood pressure shot up to 185/38, heart rate was at times over 120, mood swings were constant, I gained 30 lbs within a couple of months and felt like a raging bull on most days. I’ve found from my own research that those with acute sarcoid may react positively to a low dose of steroids as compared to those with chronic sarcoid. In any case, steroids shut down the immune system and allow the disease to progress. In my case I was in a flare and the high doses of daily steroids were causing my body extreme stress.

At this particular time, I had taken a leave of absence from my position as a Flight Attendant and was in bed 24/7. I was unable after starting the steroids to stand for more than a few minutes, my muscles had atrophied, along with fatigue worsening. As my condition seemed to deteriorate daily, I was becoming hopeless.

A nurse contacted me after reading my posts online, with a research protocol that she was treated with, and was responding to, called The Marshall Protocol (MP). After reading about it for over a month, I recognized much of what the protocol studies were exposing to be classic symptoms of what I had gone through for so many years. It was at this point, from listening to my body signals, that I opted for this alternative treatment. (Note: This protocol is based on Federal Drug Administration approved drugs, avoidance of vitamin D, and steroid avoidance.)

Symptoms that other doctors seemed baffled with mirrored mine: extreme light sensitivity, sensitivity to foods such as fish, milk, eggs, sun exposure worsening symptoms. All pointing to Vitamin D complications. I had the required D tests done for the MP protocol, the D metabolites, which include 1,25 dihydroxyvitamin-D and 25 hydroxyvitamin-D. Although 25-D is a common test, the important 1,25 is not commonly ordered and can be expensive. There was my clue that I was in trouble as the 1,25-D came back high and out of the normal range. In people with sarcoid, infected white blood cells convert 25-D to 1,25-D independently of the kidneys, causing levels to rise above what the body requires. According to the MP, elevated 1,25-D makes it easier for the bacteria to move in and out of cells, protecting them from the immune system. As more bacteria are able to parasitize white blood cells, they in turn produce still more 1,25-D. This vicious cycle largely accounts for the chronic nature of those illnesses classified as Th1 diseases, of which sarcoidosis is one. Another test for general inflammatory activity — besides measuring the level of angiotensin converting enzyme (ACE) — is the C-reactive protein (CRP) test. A cardiac hs-CRP is specific to the heart inflammation. When first tested, my cardiac CRP came back at over 9 mg/L, identifying high cardiac inflammation (1.0 to 3.0 indicates an average risk and above 3 indicates a high risk).

Began weaning from the steroids, using Benicar as required following protocol guidelines. Benicar [AF this is the trade name for one brand of olmesartan] is an Angiotensin Receptor Blocker (ARB), which works in two ways: a palliative action by blocking the Nuclear Factor-kappaB cytokine pathway, and an action whereby it activates the Vitamin D receptor (VDR), and gets the innate immune system working again. By the end of three months, I had stopped taking steroids. Within six months I was through Phase I of the protocol. Phase I involves, as well as the Benicar, taking small well-spaced doses of the antibiotic minocycline.

Once into Phase II of the protocol, I began seeing monthly improvements that were gauged by not only how I felt but also with my blood work. Not only did I see improvements in my current health issues but lingering health issues were beginning to correct themselves. Symptoms that I had never associated with my undiagnosed sarcoid. Sinus issues cleared, ear problems cleared, jaw problems cleared, tooth pain cleared, irritable bowel syndrome (IBS) was improving, neck and head pain cleared, “internal shakiness” cleared, eyesight in my left eye improved, although I had been assured by my ophthalmologist that it was optic nerve damage and would never repair. This improvement was confirmed with a visual field test. Brain fog, which has been extreme at times for many years and a battle to live with, continues to improve.

Eighteen months into the protocol, I was able to return to my job. It was an emotional time for me after being so ill for so long. I could not have anticipated returning to work. My doctor who treats me with the MP was thrilled. I am currently three-fourths of the way through Phase II and will move to Phase III, the final phase of the protocol, hopefully, in a few months. Phase II and III essentially consist in using several other antibiotics, again in small well-spaced doses. I continue to deal with herx (also called immunopathology

reaction, IP or IPR) which is an increase in present inflammatory symptoms, or a return of previous inflammatory symptoms, that, according the MP theory, is caused by cytokines and endotoxins being released from the dying bacteria.

With Phase III, being the final Phase of the protocol, I look forward to continued improvements and healing. For me finding the protocol answered many questions that had long gone unanswered, with my many years of extreme health issues. It is sad to think of going almost 20 years without a diagnosis but I am today so grateful for my progress.

Dr. Marshall's work is now being recognized in key areas around the world. Dr. Marshall has been asked to keynote a conference on Gene Technologies, chair a conference session on Autoimmune Disease and publish a number of peer-review papers. West China Hospital, the largest Clinical Center in the world, has signed an agreement to collaborate in bringing the therapy to China, initially for autoimmune diseases.

A PATIENT'S VOICE

Inspiring and practical advice about living with Chronic Health Conditions, such as cancer and Sarcoidosis. And achieving Positive results regarding all your Health Care needs — All written from a Patient's Perspective and personal experience.

Gilbert Barr Jr.

iUniverse, Inc., www.iuniverse.com; ISBN 978-1-4401-1988-0; 235 pages; \$19.95

A review by Heather Walker

This is Gilbert Barr Jr.'s third and last book. His previous two books, *Me and Sarcoidosis: A Patient's Story about living with a chronic health condition*, and *Living with Sarcoidosis and other Health Conditions*, will be familiar to readers of SILA's newsletter, as will Gilbert Barr Jr.'s approach to his life and to his health conditions. His positive attitude to his problems (as indicated by the title) provides a useful explanation of what is to follow. Gilbert Barr recognises the wide influence of chronic illness in the patient's life, and how this permeates a patient's existence to include his or her family, friends, carers, work, and relationship with the medical profession.

Gilbert Barr Jr. was born at Florida USA in 1958, and although the system of medical care in the USA differs from the NHS, and some problems (such as health insurance, etc.) when dealing with sarcoidosis may differ at times, Barr's book has ample information for sarcoidosis patients from both sides of the Atlantic to enable them to deal with day to day and long term consequences of their illness. The experiences can be divided into practical and emotional; and now Barr has cancer (as did his father) he does not shy away from describing his giving way to despair, or problems resulting from sexuality that other writers might shirk to share frankly with the reader. Neither does he mute his descriptions of the changes that treatments for sarcoidosis and cancer can bring, along with guilt about 'being a burden' to loved ones.

Gilbert Barr refers to himself as a 'Professional Patient', a title I think he deserves after writing these three books.

Three years on – a modest success with cetyl myristoleate: Mar 08-May 2009 update covering the three people currently participating in the Small Scale Trial No. 1, using cetyl myristoleate to alleviate chronic sarcoidosis

Abstract.

Practically every case of sarcoidosis is idiosyncratic, but there does seem to be one useful generalization, namely that chronic pulmonary sarcoidosis is unlikely to get better without treatment. That made it a particularly useful form to study. However there are many complications that can arise, making it hard to draw conclusions. One notable conclusion of this study is that in the most carefully monitored of the three cases, the overall improvement of 80%, rated after three years, is sufficient to conclude that in similar cases, cetyl myristoleate (CMO) is something that should be tried before proceeding to use steroids. The other two cases have only reached their two year point. Not a great deal can be said about them except that so far the fairly marginal improvements have been sufficient to avoid the use of steroids.

There is a reminder of the early experiments with Voltarol Emulgel P (*diclofenac diethylammonium*), a very dilute form of gel that is off-prescription, which for over a year was moderately successful, indicating that, in view of the dire problems caused by corticosteroids, NSAIDs should be investigated more thoroughly.

The first of three cases of intermittent treatment with cetyl myristoleate (CMO) for chronic pulmonary sarcoidosis — Andrew's Story Part 3.

This first section is to a considerable extent a continuation of *Andrew's Story*, Part 1 of which appeared on pages 11-13 of SILA News No. 20, and Part 2 on pages 6-17 of SILA news No. 21 (Summer/Autumn 2007). Since I am writing this in late May 2009, there has been a long gap since the last report. That is explained by the fact that nothing much of obvious significance has been happening.

It was on 18 March 2006, just over three years ago, that I started an experiment in treating my chronic pulmonary (lung) sarcoidosis with cetyl myristoleate (CMO). One reason for delaying beyond 18 March 2009 in compiling a 3-year update report was that there are two other people in this fairly informal trial. On 24th April, two years had passed since Tim T started a similar treatment, and on 16th May, Rosemary H also reached the end of the second year from when she commenced similar treatment. All of us are chronic cases of sarcoidosis, with lung problems being the most easily observed clinical symptom. However, as is common with sarcoidosis patients, we all suffered from intermittent extreme fatigue. All of us had reached a point in deterioration of lung function when it seemed inevitable that we would have to go on to steroids. One 'advantage' of our particular form of sarcoidosis — as far as this study is concerned — is that specialists are almost unanimous in saying that chronic pulmonary sarcoidosis won't go away unless treated; moreover it is likely that eventually the deterioration will be such that there will a choice between treatment and death!

Although none of us have had to go onto steroids, the exact part that cetyl myristoleate has played is not easy to ascertain. The most clear cut, and certainly most accurately

observed, case was myself, so I will start there, and then go on to relate the relatively little that can be deduced from the experiences of Rosemary H and Tim T.

I will try to make this report self-contained, so for those who have not read the earlier reports, I should say that cetyl myristoleate is most probably the active ingredient in a mixture of fatty acids known as CMO. The substance has only been studied as a treatment for arthritis. It undoubtedly has had some success in that regard (in one case I know of personally, there has been a long-term spectacular success, and most people, including me, seem to find it helpful for various arthritic-type pains). Unfortunately the substance was impossible to patent, so, following early reports of success, selling it in various forms became a scam (the variable nature of arthritis makes it a good basis for scams). However there is one firm which I know of, EHP Products Inc.,¹ which can be trusted to be selling the genuine article, and they sell over the internet at prices which are far below some of the scam organizations.

Since it is nearly two years since I made my last report, I will rehearse some of the details mentioned earlier. One general point I should mention is that although there are clinical tests, such as spirometry, which measure lung function, they tend to be too infrequent to be useful monitors (see later section on this), so I devised my own method, namely measuring the number of steps per respiration cycle that I could keep up when covering a 500 metre course. Each test also involved a separate 200 metre course up a one in twenty (5%) slope, but that distance is rather short to be accurate.

One thing that still seems compelling to me as an argument that cetyl myristoleate has been of instrumental importance is that for the year preceding commencement of cetyl myristoleate treatment (18 March 2006) I was using a topical non-steroidal anti-inflammatory drug (NSAID) Voltarol Emulgel P (*diclofenac diethylammonium*). It was initially consistent in its beneficial effects: during the space of a month it raised my steps per respiration cycle from 5 up to 8 each time I used it. But then a plateau was reached, so I stopped using it (extended use is inadvisable), after which the steps per respiration cycle dropped back to 5 within a few months. Moreover towards the end of the period, a peak of only 7 could be reached; furthermore, the drop off in lung function thereafter (back to 5 steps per respiration cycle) took only 3 weeks. The significance of that year of using *diclofenac* is threefold: (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; (c) it indicates a need to study NSAIDs. To put flesh on 5 steps per respiration cycle, I will add that the twenty-five minute walk into town, and back to where I live near the top of a moderate hill, was becoming quite an ordeal. Five steps per respiration cycle was the point at which I decided something had to be done (my doctor advised me not to go onto steroids until I felt something had to be done).

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 last three years* following that rise to 6.9 steps per respiration cycle, lung function on level ground has never dropped below 6.6 steps per respiration cycle. Also, on the roughly 1 in 20 upslope, lung function has never dropped below 4.6 steps per respiration cycle. The latter is only a 35% improvement on the initial 3.4 steps per respiration cycle, but 4.6 was an unusually low measurement. The averages so far for 2009 are 7.8 on level ground and 5.5 on the upslope. Both represent an approximate 55% improvement on the starting values 3 years ago. These are not dramatic improvements, but they allow life to continue without too many restrictions. Moreover lung function, although ultimately life threatening, was not the only thing that seemed to me of primary importance when I started cetyl myristoleate treatment.

Attempting a broader estimate of progress

When I started the CMO experiment, partly in order to make sure it was a *prospective* experiment rather than a *retrospective* survey of what medical conditions happened to have improved, I set out various ailments that it seemed possible the CMO might affect. I tried to estimate the proportions of the total medical problem that each ailment comprised in terms of damaging a good quality of life. This is what I said (in square brackets are the current improvements, but related to *sarcoidosis* symptoms only,):

- 1) **10%** Stomach ache (troublesome only at nights).
- 2) **20%** Sarcoidosis and breathing. **[35%, see explanation below]**
- 3) **10%** Sarcoidosis and coughing. **[100%]**
- 4) **45%** Sarcoidosis and Totally Erratic Exhaustion Syndrome (TEES). **[100%]**
- 5) **10%** BPH (Benign Prostatic Hypertrophy, causing frequent nocturnal urination).
- 6) **3%** Sarcoidosis and dry eyes. **[50%]**
- 7) **2%** Right shoulder (discomfort in same on certain movements).

The sarcoidosis symptoms represent 78% of the total. Taking this assessment of importance into account, the overall improvement in the sarcoidosis symptoms can be assessed as $(20 \times 0.35) + 10 + 45 + (3 \times 0.50) = 63.5\%$, for an overall improvement in sarcoidosis symptoms of $63.5 / 78 = \underline{80\%}$.

I won't repeat the rather lengthy explanation I gave on page 9 of SILA News No. 21 about how I assess how lung function improvement is compared to 'normal'. The important point is that when, three years after starting treatment, all troublesome aspects of my sarcoidosis experience are taken into account, the overall improvement is 80%.

Diverting briefly from sarcoidosis, it may be of interest that after much experiment I have almost completely overcome the stomach ache problem by taking a 500 mg Turmeric tablet with my evening meal. The last item on the list above, problems with the right shoulder, appear to be resolvable with cetyl myristoleate cream. It took some months to chase the problem away to start with, but now, when occasionally it returns, a few days of treatment with Myristin Topical Cream improve it so much that I soon forget to go on applying the cream! The same appears to be true of my cough. If I notice it coming back, I apply a little Myristin Topical Cream to my throat and within a few days it has gone

away. Since I don't know whether it was really the sarcoidosis cough coming back, I have assessed a 100% improvement to the persistent cough problem.

Although there is no doubt about the fact that cetyl myristoleate initiated the improvement in lung function, and stopped my persistent cough, and eliminated the fatigue problem, it has been difficult to prove a subsequent relationship between the use of it and improvement in lung function. In previous reports, I included comprehensive graphs of changing lung function, but I think the job will be better done now with a summary of what might be significant (also the graph on the next page gives a wide perspective).

During the period 22 Aug 08 to 29 Nov 08, I took one Myristin Softgel each day. Each 650 mg capsule contains 260 mg of cetyl myristoleate, so that was a significantly higher dose than using Myristin Topical Cream. On the other hand, because I was taking it orally, and should have been keeping off alcohol and caffeine, but wasn't, the experiment was less than perfect. During the period, the result was that I maintained a fairly consistent and satisfactory lung function, averaging 8.4 steps per respiration cycle (although that's still only about 70% of normal).

Since 1st Dec 2008, I have been using only Myristin Topical Cream, applying it at about the rate of 70 mg of cetyl myristoleate per day (1 pot lasts about 40 days at that rate). In the first few weeks after switching to the cream, there was a drop of about 1 step per respiration cycle, but over the following approximate 5 month period the average has been 8.0 steps per respiration cycle, so overall there has not been much change. Incidentally when I switched to using the Myristin Topical Cream (using it rather liberally at first), because I believe that it is *not* necessary to abstain from alcohol and caffeine when using the cream, I anticipated some further *improvement*. The fact that the reverse happened is yet another illustration that I am immune to the placebo effect.

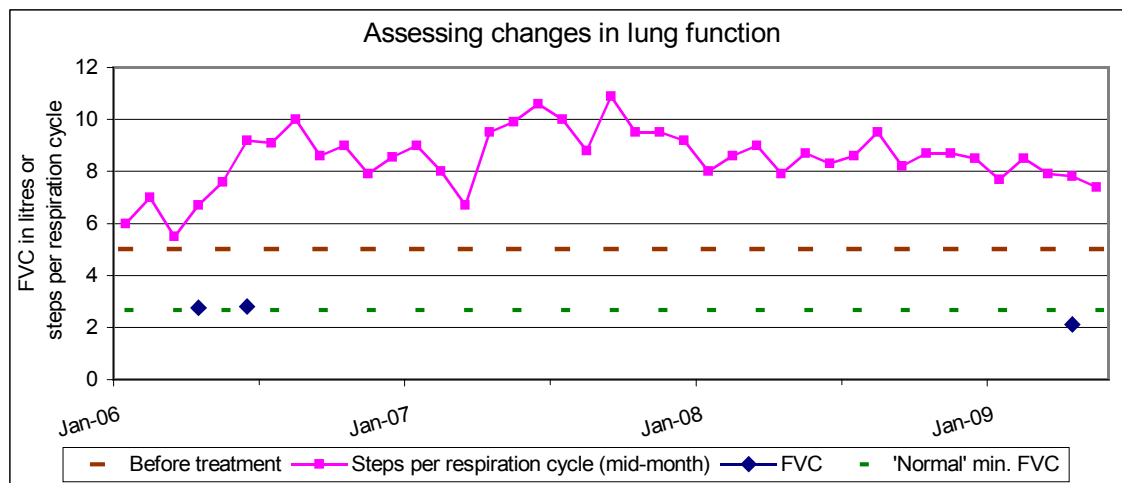
The picture would not be complete if I did not mention another health complication that is somewhat interfering with assessments. It may or may not be associated with sarcoidosis. Towards the end of May 2008, I started to notice heart irregularities (arrhythmia) and some discomfort in the area. On one occasion the heart would only get up to about 50%-75% of what it would normally do when walking (hugely slowing me down). Over the next many months I experimented with taking hawthorn (there is a good background of evidence for its effectiveness in heart conditions). I eventually found that about 45 drops of tincture per day, or two Solgar capsules, would suffice to largely overcome the problems. Nevertheless the heart seems unwilling to perform as well as it used to. However that may be a necessary penalty of the hawthorn sorting out the other problems. Anyhow I am considerably slowed down on hills. A hilly walk that used to take me 48 minutes now takes about 58. At the age of 71, there is of course the complicating factor of age. Also there is the open question of whether the heart problem is an aspect of sarcoidosis. I decided that any medical investigations that could be made were likely to be inconclusive, and anyhow I would probably be unwilling to take the dangerous drugs that would be recommended by the medical profession, so I have not sought to clarify the answer to whether the problem is sarcoidosis related. It is true that cardiac sarcoidosis does fairly often develop from pulmonary sarcoidosis, so it may be.

Spirometry measurements

It is of interest whether a spirometer (the hollow tube that one blows into), which measures the Forced Vital Capacity (FVC) echoes the steps per respiration cycle measurements. The

first two diamonds in the figure below, representing spirometry measurements, were taken on 26 Apr 06 (FVC 2.77) and 13 Jun 06 (FVC 2.82). I had two measurements taken within two months because I was interested to see whether the spirometer would identify the improvement in lung function that was occurring rather rapidly at that time. It did just, showing a 2% improvement from 2.77 litres to 2.82 litres, but it is evidently a weak method of assessment, which explains my not using it for almost the next three years.

By way of further explanation, the lower dashed line shows the minimum (2.66 litres) of the 'normal' FVC range, that applied at the *last* reading (the actual 'normal' at that time was 3.66 litres and the maximum 4.66 litres). Changes with age are fairly small. The minimum which applied at the time of the first reading was 2.74 litres instead of 2.66.



It was not until 15 Apr 09 that I had another spirometer check. At 2.13 litres, FVC is a shade lower than I would have expected for the then current steps per respiration cycle, but it is possible that the spirometer reading was slightly low, as it occurred to me later that the nurse had not suggested I should make the maximum effort to draw in breath before blowing through the tube. As nearly three years had passed since my last spirometer test, I had become a bit hazy about the finer details of the procedure!

Incidentally the sharp dip in the graph around March 2007 was caused by a temporary cough/cold. The graph highlights some unanswered questions. Why did the steps per respiration cycle get so high but then drop off? The peak was 10.9 (about 90% of 'normal'), while the last reading was 7.4. It is possible that the slight problems with my heart may be a relevant factor. It is very difficult to get a measure that is accurate, useful, and avoids all sources of error. During the last session, the nurse put a finger-tip oximeter on one finger and, seeing the reading was 96%, said that seems fine, but I expect exercise is necessary to make such measurements really useful. One important point in favour of steps per respiration cycle is that it represents a measure of what one actually wants to be able to achieve, namely take some exercise and have some breath left over for doing other things, like talking!

Preliminary conclusion

At three years into the experiment, some conclusions can be drawn from my own experience. The initial improvement at the start of the period cannot be explained plausibly except as the effect of the cetyl myristoleate treatment. On the other hand, the fairly variable level of improvement that there has been since then shows no clear

correlation with the further use of cetyl myristoleate. There is nevertheless some general evidence that cetyl myristoleate has been important, because there is a very high probability that by now, three years after most doctors would say “something has to be done,” I can claim an 80% improvement. It seems reasonable to conclude that since the administration of this harmless substance, sold as a food supplement, may delay the use of steroids for several years (and it remains to be proved that steroids promote ultimate recovery – rather they limit damage), it would make a lot of sense for *chronic pulmonary sarcoidosis* sufferers to at least try a pot of cetyl myristoleate cream (cost about \$15) to see if it has the notable effect which has occurred in my case. However the situation with the other two patients is less clear cut. We will turn to them now.

Rosemary H

Rosemary H, one of the two people helping me investigate cetyl myristoleate, was never an entirely suitable patient for this trial because since childhood she has always been troubled with chest infections. In recent years, each time the problem reached crisis proportions, she was given antibiotics. Initially that seemed to have a good effect, but the effectiveness diminished. Her doctor gave her antibiotics to keep in reserve, to take as soon as the problem became apparent; that helped a bit. Until recently the antibiotics prescribed were not the tetracyclines minocycline or doxycycline, which is a pity as these are the antibiotics that have been shown to be effective against skin sarcoidosis, and at least beneficial in improving other sarcoidosis symptoms.²

One challenge therefore was to stop Rosemary getting a chest infection. There is fairly good evidence that quercetin is helpful in avoiding chest infections, so during the winter, on my advice, each day she took one of Solgar’s Quercetin Complex capsules (250 mg quercetin, 250 mg vitamin C). It may well have been a coincidence, but shortly after she stopped taking them, winter having ended, she once again developed a chest infection. Her new doctor prescribed doxycycline. The full story on that is unfolding, but those details will suffice to explain why it is hard to interpret her results with cetyl myristoleate.

To recap on her story, it is pertinent to note that at the start her lung function was at 4 steps per respiration cycle, and that her consultant told her 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 on 16 May 2007. But within two weeks of starting to apply Myristin Topical Cream, Rosemary’s lung function had improved to 6 steps per respiration cycle. She also felt much better with regard to her fatigue problem.

Covering briefly the subsequent two years (given in more detail in an earlier report), although her specialist signed her off, as being in remission, the subsequent effect of cetyl myristoleate has been hard to discern, rather as it has with me. Moreover, unlike with me, fatigue has continued to be a major problem. Almost the only positive things that can be said about her case are (a) that her specialist thought it was inevitable that she would have to go onto steroids and that he was surprised at her rather rapid initial improvement; and (b) she has managed to keep off steroids for two years.

It is evident from studying the sarcoidosis Social Network that it is very difficult to find what might be considered ‘uncomplicated’ cases of sarcoidosis which are suitable for study, namely those whose cases are chronic — and so unlikely to cure spontaneously — and have only the most common symptoms of sarcoidosis — poor lung function, persistent cough, and fatigue. The advantage of confining attention to these symptoms is that, in

combination, they are likely to be caused by sarcoidosis and not by other health problems. It was mainly because Rosemary was keen to try cetyl myristoleate — on the chance that it might avoid the use of steroids — that she was enlisted as part of the trial. Unfortunately her chest infection complications will always make it hard to draw conclusions. At least it seems unlikely that she has suffered further loss of lung function since she started cetyl myristoleate treatment two years ago. However she reports almost no change in fatigue. She has a new doctor who is apparently willing to listen (and as mentioned prescribed doxycycline), so this story, covering only two years so far, is still unfolding.

Tim T

Tim T is the other person helping me with my enquiries. There is a different sort of 'research problem' with Tim, namely that he is one of those who only pay attention to their health when they have to. If such people feel they can manage, then the last thing they want to think about is their health. Thus there is not much more to relate about Tim than could be said a year ago.

To recap his story briefly, he was very keen to avoid going onto steroids, or 'waste' time with doctors, so had allowed himself to get down to 3.5 steps per respiration cycle (fatigue was also a problem with Tim). 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 has used no more cetyl myristoleate. 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.

That was the situation when I last reported on Tim, when he was nearly a year into his trial. About all he can say now is that things have not changed much since then. His wife says that he is more energetic than he used to be, but Tim says that fatigue is much the same. One thing that can be said for certain is that he has not needed to go onto steroids.

Write up by Andrew Ferguson, but with the approval of other participants.

Three cases of sarcoidosis treated with combined pentoxifylline and doxycycline

[AF. With some additional annotations, below is a paraphrase of the original report on page 17. I would suggest that a suitable subtitle for this report would be: “Three patients manage to persuade doctor to use harmless and effective treatment for sarcoidosis, after suffering for many years the adverse effects of the standard treatment offered by the medical profession!” Here is a simplified and jargon free version of the report on p. 17.]

Combined Pentoxifylline and Doxycycline as a Steroid-sparing Adjuvant Regimen in Sarcoidosis [AF. i.e. Combined Pentoxifylline and Doxycycline used as an alternative to the damaging drugs that doctors usually use.]

William D. Marino, MD*

Our Lady of Mercy Medical Center, Bronx, NY

PURPOSE: Many of the complications of sarcoidosis are caused by its steroid therapy. These include diabetes mellitus, osteoporosis and infection. [AF. And of course there are many more dire effects suffered by some people.³]. Standard steroid sparing agents either have severe side effects or are relatively ineffective (antimalarials [AF. ‘Antimalarials’ refers to chloroquine and hydroxychloroquine. Marino may be a bit misleading in stating that antimalarials are relatively ineffective, insofar as Baughman et al. assert that, with respect to skin sarcoidosis, “Chloroquine and hydroxychloroquine have been found to be effective in over half of the reported cases.”]). Pentoxifylline has shown activity against mild sarcoidosis while doxycycline is active against cutaneous sarcoidosis [AF. I wonder whether, with respect to doxycycline, this assertion is based on the Bachelez et al. 12 person trial, or whether there has been some follow up to that encouraging trial. I have not been able to find out who discovered that pentoxifylline is beneficial]. Three of our sarcoidosis patients developed significant steroid side effects but refused standard alternatives, fearing further complications. They found internet references to the use of doxycycline and pentoxifylline in sarcoidosis and requested their use. The results of their therapy are presented here. [AF. In reading what follows, it is useful to know that the report was made in October 2008.]

METHODS: The treatment regimen was pentoxifylline 400mg taken orally twice a day (800 mg total) and doxycycline 100mg taken orally twice a day (200 mg total). [AF. 200 mg/day was the dosage used by Bachelez et al. although initially they used minocycline, only later doxycycline.]

RESULTS: All 3 patients have had sarcoidosis requiring more than 30 mg/day of prednisone for 10 years or more. They have consistently refused supplementary drugs and referral to other specialists.

1) A 59 year old woman developed obesity and sleep apnea on 60 mg/day of prednisone. She began pentoxifylline/doxycycline in April, 2007. Her prednisone dose is now 10 mg/day with stable pulmonary function. [AF. Even were this lady to be completely clear of sarc, she would probably need more than 18 months to wean off 60 mg/day of prednisone. Note the implication that the pentoxifylline/doxycycline regimen was implemented alongside the use of prednisone.]

2) A 53 year old woman using prednisone 40 mg/day began pentoxifylline/doxycycline in

March 2007 because of diabetes. She has been off prednisone since February with no suggestion of disease activity.

3) A 49 year old woman on more than 30 mg/day of prednisone for 20 years developed diabetes and a type of pneumonia (CMV). She began doxycycline/pentoxifylline in September 2007 and has now been off prednisone for 2 months with stable pulmonary function.

ACE levels, [AF. Angiotensin Converting Enzymes provide a somewhat erratic indication of whether the body is trying to combat a problem.] high in all 3 patients during disease previously, are normal. None has reported treatment side effects.

CONCLUSION: This regimen reduces corticosteroid requirements in sarcoidosis with little treatment complication. [AF. My own further conclusion: the failure of doctors to investigate the use of antibiotics after the success of the Bachelez et al trial⁴ until ‘forced’ to do so by their patients is shameful!]

CLINICAL IMPLICATIONS: This regimen should be considered when sarcoidosis patients develop steroid complications but refuse standard regimens. [AF. A rubbish conclusion! Doctors should be willing to propose these treatments to patients who are having significant problems with the standard regimens, which problems are likely to be suffered by a high percentage of patients.]. Many patients will find similar treatment options on the internet, and physicians must be able to discuss them meaningfully. [AF. i.e. doctors should start learning from their patients. Hear! Hear!]

DISCLOSURE: William Marino, No Financial Disclosure Information; No Product/Research Disclosure Information

I hope that is of interest and that some of you are lucky in having a doctor willing to give a similar regimen a try. I would like to be able to say more on the evidence on:

- (a) the usefulness of pentoxifylline on its own;
- (b) why someone, and these three patients in particular, thought that it would be beneficial to try the combination of pentoxifylline and doxycycline
- (c) how the dosage of pentoxifylline was arrived at (the doxycycline seems to be following Bachelez et al), but I have no information on those points.

There is no separate entry in the British Medical Association’s *Concise Guide to Medicines & Drugs* regarding pentoxifylline, but in the index it says that it is: “a vasodilator [AF. Drugs that widen the blood vessels.] used to improve blood flow to the limbs in peripheral vascular disease. Previously known as oxpentifylline.” But the BMA’s 2007 guide seems not to be up to date, as Deedee (member of the Social Network) has discovered that it also serves to reduce the Tumour Necrosis Factor (TNF), which is produced by macrophages (a type of white blood cell that’s part of the immune system) and helps create granulomas. Clearly that may be significant to treatment of sarcoidosis.

Andrew Ferguson

Tuesday, October 28, 2008 1:00 PM - 2:15 PM

COMBINED PENTOXIFYLLINE AND DOXYCYCLINE AS A STEROID-SPARING ADJUVANT REGIMEN IN SARCOIDOSIS

William D. Marino, MD

Our Lady of Mercy Medical Center, Bronx, NY

PURPOSE: Many of the complications of sarcoidosis are caused by its steroid therapy. These include diabetes mellitus, osteoporosis and infection. Standard steroid sparing agents either have severe side effects (antimetabolites, thalidomide and TNF α binding agents) or are relatively ineffective (antimalarials). Pentoxifylline blocks secretion of TNF α and has shown activity against mild sarcoidosis while doxycycline inhibits matrix metalloproteases (remodelling enzymes) and is active against cutaneous sarcoidosis. Three of our sarcoidosis patients developed significant steroid side effects but refused standard alternatives, fearing further complications. They found internet references to the use of doxycycline and pentoxifylline in sarcoidosis and requested their use. The results of their therapy are presented here.

METHODS: Data on disease activity, physiologic function and anthropometrics were obtained from PFT records and patient charts. The treatment regimen was pentoxifyllin 400mgPO BID and doxycycline 100mgPO BID.

RESULTS: All 3 patients have had sarcoidosis requiring more than 30 mg/day of prednisone for 10 years or more. They have consistently refused adjuvant regimens and outside referral. 1) A 59 year old woman developed obesity and sleep apnea on 60 mg/day of prednisone. She began pentoxifylline/doxycycline in April, 2007. Her prednisone dose is now 10 mg/day with stable pulmonary function. 2) A 53 year old woman using prednisone 40 mg/day began pentoxifylline/doxycycline in March 2007 because of diabetes. She has been off prednisone since February with no suggestion of disease activity. 3) A 49 year old woman on more than 30 mg/day of prednisone for 20 years developed diabetes and CMV pneumonia. She began doxycycline/pentoxifylline in September 2007 and has now been off prednisone for 2 months with stable pulmonary function. ACE levels, high in all 3 patients during disease previously, are normal. None has reported treatment side effects.

CONCLUSION: This regimen reduces corticosteroid requirements in sarcoidosis with little treatment complication .

CLINICAL IMPLICATIONS: This regimen should be considered when sarcoidosis patients develop steroid complications but refuse standard regimens. Many patients will find similar treatment options on the internet, and physicians must be able to discuss them meaningfully.

DISCLOSURE: William Marino, No Financial Disclosure Information; No Product/Research Disclosure Information

[It is unusual to find a study that monitors patients for as long as ten years, and there are some points of interest in this study. It is a pity that it is very poorly written up. Sometimes it is confusing (as noted), and more importantly it does not give a clear answer to what should be the key question: how much better the methotrexate-only patients (37% of the group) did compared to patients receiving methotrexate and steroids (63% of the group). For greater lucidity, I have somewhat improved the English and added some percentage figure (in square brackets). One thing that seems fairly definite is the statement “26 patients are off the therapy and did not experience a relapse of sarcoidosis after 5–10 years of follow up.” 26 amounts to 19% of the 139 patients, but exactly what is meant by “did not experience a relapse” is uncertain, especially as the authors define a “complete response” as merely, “improvement of the chest x-ray and improvement of the clinical symptoms and signs of extra pulmonary disease.” Moreover logically they must mean “*and/or* improvement of the clinical symptoms,” since only 92% of patients had lung sarcoidosis, so the remaining 8% could not show improvement of chest x-ray. Andrew Ferguson]

THE TEN YEARS FOLLOW-UP STUDY: METHOTREXATE IN THE THERAPY OF CHRONIC SARCOIDOSIS

Violeta Vucinic, PhD, Jelica Videnovic, PhD, Snezana Filipovic, MD and Vladimir Zugic, PhD Institute of Pulmonary Diseases, Belgrade, Serbia

PURPOSE: This ten years follow up study analyses the efficiency of orally administered methotrexate as a steroid sparing agent or single agent in the treatment of patients with chronic sarcoidosis.

METHODS: 914 biopsy positive sarcoidosis patients were analyzed. Out of this group 139 patients were treated with low dose methotrexate during the chronic course of pulmonary and extra pulmonary sarcoidosis. 128 patients [92%] had lung sarcoidosis and 80 [58%] patients extra pulmonary sarcoidosis including: eye sarcoidosis 50 patients [36%], skin 40 patients [29%], heart 15 patients [11%], liver 10 [7%] patients, spleen 6 [4%] patients, bone disease 7 [5%] patients, lymph nodes involvement 7 [5%] patients, thyroid gland 4 [3%] patients, neurosarcoidosis 14 [10%] patients, and bone marrow 3 [2%] patients. Out of the whole group 52 [37%] patients were treated with methotrexate only, and 87 [63%] patients were treated with corticosteroids at the same time. Complete response to the therapy was defined as improvement of the chest X-ray and improvement of the clinical symptoms and signs of extra pulmonary disease. [AF. As already noted, logically the authors must mean “*and/or* improvement of the clinical symptoms.”]

RESULTS: Chest X-ray improvement occurred in 80% of patients after 6 months of treatment: 70% of patients receiving prednisolone at the same time [AF. 80% constitutes 111 patients, and 70% of them constitutes 78. Were the prednisolone to have no effect, then one would expect, *by chance*, the 63% also taking prednisolone, i.e. 70 of them, to be in the improvement group. Thus there is only a slight indication that receiving prednisolone at the same time was beneficial.] decreased [AF. It is not made clear when it

was decreased.] daily steroid dose to 10 to 5 mg. First improvement of extrapulmonary disease was noticed 6 months after initiation of the therapy. A complete response was noticed in two cases of neurosarcoidosis with hydrocephalus 7 years after the first administration of methotrexate into the treatment. Patients, who experienced relapse of sarcoidosis after the therapy, were treated successfully with methotrexate again. (25 patients). 26 patients are off the therapy and did not experience a relapse of sarcoidosis after [AF. Presumably the intended meaning is “during” rather than “after”] 5–10 years of follow up. [AF. Presumably this 26 is out of the whole group of 139, i.e. 19%, but as written this is highly confusing because it is not clear if the 25 patients who “were treated successfully with methotrexate again” are to be included in the 26 who “did not experience a relapse of sarcoidosis after 5-10 years of follow up.”]

CONCLUSION: Low doses of orally administered methotrexate were well tolerated. During the therapy no adverse effects needed the discontinuation of methotrexate were noticed. [AF. It is most unfortunate that details are not given which clarify the meaning of “low dose.” The BMA’s *Concise Guide to Medicines & Drugs* tells us (p. 308):

Methotrexate is an anticancer drug used, together with other anticancer drugs, in the treatment of leukemia, lymphoma, and solid cancers such as those of the breast, bladder, head, and neck. It is also used to treat severe uncontrolled psoriasis until less potent drugs can be reintroduced. It is also used to modify, halt, or slow the underlying disease process in severe acute rheumatoid arthritis that has not responded to other treatment. Once the condition is under control, the dose of methotrexate is reduced to a minimum.

Thus sarcoidosis is not mentioned, and so the information that is given on dosage is not particularly relevant, but for what it may be worth, this is what is said:

Frequency and timing of doses *Cancer* single dose once weekly or every three weeks. *Other conditions* Usually, single dose once weekly.

Adult dosage range *Cancer* Dosage is determined individually according to the nature of the condition, body weight, and response. *Rheumatoid arthritis* 7.5-20 mg weekly. *Psoriasis* 10-25 mg weekly.

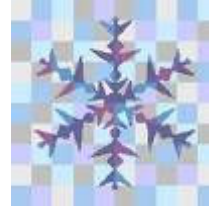
The list of possible adverse effects is long, and some adverse effects are common, moreover they have often been reported in this network, so the fact that “During the therapy no adverse effects needed the discontinuation of methotrexate” indicates some probability that low dose might mean as little as say 5 mg weekly. We could do with much more sharing of information about frequency and amount of doses on the Social Network, as the medical profession are not forthcoming on such matters. There are at least a few doctors who specialise in sarcoidosis who impress their patients, particularly some at the Royal Brompton. They should surely know what was meant by “low dose” in this report.]

CLINICAL IMPLICATIONS: Low doses of orally administered methotrexate are highly recommended in the therapy of chronic sarcoidosis for its low side effects as the single agent or steroid sparing agent in the therapy of chronic sarcoidosis.

DISCLOSURE: Violeta Vucinic, No Financial Disclosure Information; No Product/Research Disclosure Information.

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 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 website

SILA's AGM will be held on Thursday October 1st 2009 at 7pm in the Boardroom, King's College Hospital. All fully paid-up members of SILA can vote at the AGM. Afterwards there will be the usual Support meeting until 9 pm..

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

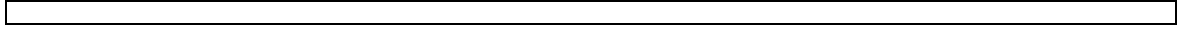
Freedom Insurance Services Ltd.,
Richmond House
16-20 Regent Street,
Cambridge CB2 1DB

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
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 . EHP Products, in the USA, has a website at <www.cetylmyristoleate.com>. Address is EHP Products, PO Box 2017, Mt Pleasant, SC 29465, USA. Tel: (843) 881-5700. They are a good firm to deal with, and I have only one complaint about their website. They seem to confuse the meaning of cetyl myristoleate and CMO, the former being probably the only active ingredient in a mixture of fatty acids known as CMO. In at least one place they refer to cetyl myristoleate as “elemental CMO,” which is a term with no inherent meaning.
- ² . A paper by Bachelez et al., *The Use of Tetracyclines for the Treatment of Sarcoidosis*, reports on an excellently conducted trial of 12 patients with skin sarcoidosis who had not responded to antimalarial drugs. It is available in full (5 pp.) at <http://archderm.ama-assn.org/cgi/content/abstract/137/1/69>
- ³ . Members of the sarcoidosis Social Network <http://sarcoidosis.ning.com> will find a comprehensive report at: <http://sarcoidosis.ning.com/group/steroidtreatment/forum/topics/769148:Topic:125>
- ⁴ . The Bachelez et al trial is available for download as a pdf file (5 pages) at <http://archderm.ama-assn.org/cgi/content/abstract/137/1/69>