



## S.I.L.A. NEWSLETTER 20 WINTER/SPRING 2007



Dear SILA Supporter,

The year 2007 is important for SILA. It will be ten years in August since SILA received charitable status in 1997, although SILA was up and running before that date. I was thinking of the best way to celebrate this important milestone, when I was emailed with the news that a charity ball was to be held in Penarth, South Wales in March 2007 to raise funds for SILA. The email was from a sarcoidosis patient, whose wife is the Vice-Chairman of the Ladies Circle, who will be organizing the Ball. More events are planned by this organization to raise funds for SILA throughout the year.

It is also fitting that in 2007 the newsletter has a different formula and a guest editor raising new subjects for discussion. One subject, the Marshall Protocol (MP) has already been raised in previous newsletters. Members have responded to this information about the MP and its implications by asking their consultants for their opinions on MP. The response has been wholly negative, somewhat in line with the presentation on pages 3 and 4, but this I feel does not entirely end the debate. In the USA, views are less negative, and without doubt some people who have been trying the Marshall Protocol to deal with their sarcoidosis are very pleased with the results. We will thus continue to look at the MP in future issues of the newsletter. We are not yet ready to bury the prospect of a possible 'cure' — in the course of which there may well be a discovery of the cause.

Recently there have been difficulties due to security reasons in getting a room for the monthly SILA Support meetings and anyone planning to come to a Support meeting should read the note on page 16, just in case the problem is not sorted by the next meeting. The meetings will go on, even if we have to find a spare set of chairs and a table in an open space at KCH.

The Patients' Stories will continue to be an important part of the newsletter. They are useful, and there is much of interest that supporters could provide. For example, the general impression that one gets from studying the internet is that the corticosteroid prednisone is almost certain to bring problems in its wake. But at what dosage, and after how long? There are some people who are grateful for the benefit it has brought with minimal problems. Let us hear both the plusses and the minuses.

A feature of this issue is "Andrew's Story." It relates to what is to a certain extent a novel cure. The substance being used is cetyl myristoleate, or CMO in the form in which it has to be purchased. A thorough search of the internet will find many impressive accounts of the effectiveness of this substance on various forms of arthritis, but only a few anecdotal stories about its success with sarcoidosis. What is needed now is the sort of detailed account of its efficacy, or lack of it, that is given on pages 11 to 13. There is also an even more detailed account, including three graphs showing changes in lung function, on the SILA website. From the SILA home page you can choose "Treatments" and find the link at the words "personal report of his experiment.". Or you can open the pdf file directly by using this web address:  
[www.sila.org.uk/CMO.pdf](http://www.sila.org.uk/CMO.pdf).

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## Introduction

I have already mentioned that the debate about the Marshall Protocol is continuing. From some sources there is a far more positive assessment than that emanating from consultants. For instance, there is Allison Fullman's article on her mother's progress with MP as outlined in the Autumn 2005 SILA newsletter, and sarcoid patients from the USA have emailed with enthusiasm about the improvement in their symptoms and general health.

A particularly well detailed story comes from New Zealander, Guss Wilkinson. Both his wife Helena, and then he, were struck down by a severe form of sarcoidosis. She largely recovered without treatment, but he feels no doubt that his recovery is linked to his following— over three years — the Marshall Protocol. Members with internet facilities can discover his story by going to his website at [www.bugeikan.com](http://www.bugeikan.com), but it should be mentioned that his site is essentially a site for a Karate club, and that it is necessary to scroll down the list on the left hand side of the screen to find sarcoidosis. As Guss Wilkinson has kindly given permission to print out his sixteen page report, we can offer copies to those would like them. Requests to Heather Walker, c/o Chest Clinic Office, King's College Hospital, Denmark Hill, London SE5 9RS (refundable deposit £5).

While the evidence is not of exactly the objective kind that would be preferred by the medical profession, there are results coming from those who are participating in the Marshall Protocol, and reporting to Marshall. The results were shown by Marshall on a slide, as part of his presentation on 27 October 2006 to the 41st Annual Meeting of the American Academy of Environmental Medicine. Marshall estimated that 57 out of 92 sarcoidosis patients were "on the road to recovery." While that is clearly remarkable, it should be noted that this is a trial encompassing only patients who are in Phase 2 of the trial. There is no indication of the number who dropped out during Phase 1. There is also the problem, particularly with sarcoidosis, that there are sometimes spontaneous remissions, and Marshall indicates that the time to total recovery is from 3 to 5 years.

As will be apparent from pages 3-4, what chiefly troubles the medical profession is not knowing which aspect of the Marshall Protocol is doing good. If it was an easy protocol to follow, then one might say that it hardly matters, but taking broad spectrum antibiotics continually over a period of years is not something that one can undertake lightly.

SILA cannot at this stage endorse the Marshall Protocol, but with so much information on the internet, others can doubtless spend time researching it, and we would be glad to get analyses, from other SILA supporters, to strengthen the assessments planned for future issues. The two main sites are at [www.sarcinfo.com](http://www.sarcinfo.com), which is the earlier (and somewhat simpler) site, and at [www.marshallprotocol.com](http://www.marshallprotocol.com), which is the labyrinthine site mainly used by those who are actively engaged in following the Marshall Protocol.

Pages 5-13 are devoted to introducing SILA supporters to the substance already mentioned, CMO. The first six of those pages comprise a comprehensive description of how CMO came into being. It has had a difficult genesis, with pharmaceutical companies unwilling to take it up because there was nothing to patent. Then those who did take it up doing their best to conceal exactly what it was they were selling, so as to make as much money out of it as possible.

On pages 11-13 Andrew tells his story, which provides a good reason for taking an interest in CMO. As already mentioned, those who have access to the internet can get even more detailed information via the SILA website.

On page 14 is *Dave's Story* and page 15 *GA's Story*. These bring out very clearly the protean nature of sarcoidosis symptoms.

## **A presentation to the EPOS General Assembly 2006, on the Marshall Protocol**

**Abstract.** EPOS is the Netherlands based *European Association of Patients Organisations of Sarcoidosis and other Granulomatous Disorders*. Vivian Oldenburg of the DSV, the German sarcoidosis support group, *Deutsche Sarkoidose-Vereinigung e.V.*, made the presentation. He provides background information about the Marshall Protocol, which is followed by a discussion of the extent to which the protocol is based on evidence. The conclusion is that, as understood in the scientific community, it is not evidence-based.

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The moving spirit behind the Marshall Protocol is Trevor G. Marshall PhD. Here are some relevant biographical highlights:

- 1974 Papua New Guinea University of Technology.
- End of the 70s, Western Australia Curtin University.
- 1978 Masters Degree, University of Western Australia
- 1982 moved to the USA.
- 1985 gained PhD (Mathematical modelling of the Insulin Glucose Homeostasis in Diabetic and Healthy individuals).
- Specialized as CEO of YARC systems in high tech Internet publications.
- In recent years, he examined the biochemical role of the hormones Angiotensin II and Vitamin D, specializing in the disease picture of sarcoidosis.

### **His thesis**

#### **1. Sarcoidosis is caused by bacteria.**

- This hypothesis has a certain similarity to an earlier one that sarcoidosis is caused by the bacterium of tuberculosis.
- A Swedish group of researchers, Nilsson et al., published a case report about two autopsies from sarcoidosis patients. They found genetic material of the bacterium *Rickettsia Helvetica*. Biopsy samples from 30 patients were examined for *Rickettsia* and 26 were found to be positive.
- *Rickettsia* is a parasitic organism, which is transferred by ticks, fleas, mites and lice. They are responsible for different diseases (for example typhus) and can only live within living cells. *Rickettsia* are sensitive to antibiotics of the tetracycline group.
- TG Marshall's theory is that sarcoidosis and similar inflammation diseases (Th1 diseases) are not caused specifically by *Rickettsia*, but rather by a large group of very small bacteria named Cell Wall Deficient (CWD) bacteria.

#### **2. The effects of vitamin D and are not only relevant to maintaining calcium balance, but also to the formation of macrophages and giant cells, which are characteristic of sarcoidosis.**

- There is no evidence in the external (to the MP group) medical literature for this part of the thesis. Neither is there evidence for another part of Marshall's thesis, namely that granulomas produce vitamin D by themselves.
- TG Marshall believes that many of the symptoms of sarcoidosis and other Th1 diseases are caused by excess vitamin D and its metabolites (break down products). This thesis is also unsupported by external publications.

- TG Marshall recommends to avoid vitamin D not only in food, and food supplements, but also by reducing exposure to sunlight (the protocol also involves wearing dark glasses). He believes that reduction in vitamin D inhibits the growth of further granulomas. This pathological connection is not yet evidence based.

### 3. **Olmесartan is used in the Marshall Protocol in order to protect the organs.**

- The main medical use of sartans is to lower blood pressure. The Marshall Protocol involves using olmesartan at three or four times the dose used for lowering blood pressure.
- At present, the effect of sartan on protecting organs is the subject of numerous medical trials.

#### **Open questions:**

- The MP frequently causes a Jarisch-Herxheimer reaction (JHR also known as a Herx, and recently given the alternative name Immuno Pathological Reaction or IPR). The MP theory is that this arises because the bacteria are being killed off, but this is somewhat implausible in view of the fact this does not normally happen with antibiotics. What exactly is happening during these JHRs is an open question?
- The initial antibiotic used is minocycline. This is thought to have anti-bacterial, anti-inflammatory and immunomodulatory properties (as indicated in an article on sarcoidosis in the Journal of the American Association, November 2006). Treatment is over a long period (several years). Which of these properties is resulting in the improvement in symptoms where that occurs is an open question.

#### **Comment**

TG Marshall's thesis is not yet supported by evidence coming from outside the MP group.

The literature to which TG Marshall refers is in most cases his own and to publications on the JOIMR website (Journal of Independent Medical Research). This basis is not objective, to the extent that he is the webmaster of the website, and is also involved in the review group of JOIMR (see [www.joimr.org](http://www.joimr.org)).

No other scientist has taken up the study of the thesis by TG Marshall. He is carrying out an extended trial using the internet, but there are many problems with experiments conducted in this way, the primary one being that it is impossible to know how many people are dropping out of the trial at an early stage, after finding that it has little effect. There also appears to be no attempt to find out which *aspects* of the protocol are having a beneficial effect. As mentioned above, extended use of minocycline may have a beneficial effect by itself over what is normally an extended period of treatment, but the reason for the improvement may be for a variety of reasons, namely the anti-bacterial, anti-inflammatory and immunomodulatory properties.

In summary, TG Marshall's thesis at the present time is:

- Not supported by independent evidence.
- Not transparent.
- Not objective.

Analysed and presented by Vivian Oldenburg (DSV-Project on Sarcoidosis information and Assistance).

The following piece is about a substance called CMO. It may seem to be of little relevance to sarcoidosis sufferers, but the Patient's Story which follows describes a remarkable improvement using this substance, and the details make it appear highly improbable that the improvements were coincidental. Hopefully it will arouse a good deal of interest among sarcoidosis sufferers. Yet anyone considering whether to try 'yet another' unproven remedy will want, as I did, to build up a picture of the origin of the substance in question. What follows sets out to do that. Perhaps readers will be best served by first reading "Andrew's Story" (page 11). Then the reader can decide if the subject is of sufficient interest to warrant studying the following description of the origins of this possible cure for arthritis and many other auto-immune type diseases.

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## **THE GREAT CMO SCAM AND A POSSIBLE CURE FOR ARTHRITIS**

by Andrew R.B. Ferguson<sup>1</sup>

People who have not previously seen the group of letters 'CMO' may doubt the existence of any 'great scam' around it; but a Google search for CMO produces about 70,000 hits, and it is soon apparent that it is sold by many vendors. Like all good scams, the 'great CMO scam' has an element of truth at its heart. The truth is that there is a naturally occurring substance which sometimes has a dramatically beneficial effect on many forms of arthritis (and possibly on other autoimmune diseases). The 'great CMO scam' depends on that essential truth. Let us start by looking at it, and its origins.

### **Harry Weldon Diehl's research**

Around 1964, a gifted American research chemist, Harry W. Diehl, was struck by the fact that he could not induce arthritis in a certain strain of Swiss albino mice. He asked a colleague about it. The colleague replied, that if he or anyone else could manage to induce arthritis in such mice, he would want to hear about it, because he believed it was impossible! Scientist that he was, Diehl thought that the mice must contain something that prevented them from getting arthritis. Good chemist that he was, he eventually isolated a substance, cetyl myristoleate, which he thought was the "immunity agent." It was.

In his first two patents on the subject, in 1977 and 1978, he describes how he extracted the cetyl myristoleate from mice, and how he injected rats with the substance, and that this very effectively gave them immunity to arthritis. His first extracts of cetyl myristoleate involved macerating 79 mice and extracting the compound, using a somewhat complex process which is described in minute detail in his 1977 and 1978 patents.

In his 1978 patent, he also shows how to synthesize cetyl myristoleate from the fairly readily available substances, myristoleic acid and cetyl alcohol. Furthermore he showed this synthetic product to be every bit as effective as the naturally occurring substance extracted laboriously from mice. By 1978, Diehl had shown that cetyl myristoleate can be delivered by injection, orally (in capsules), or applied topically (that is to the skin, as a cream or lotion), with striking beneficial effects on some small mammals.<sup>{2}</sup>

These earlier patents related to mice and rats, and they applied to rheumatoid arthritis. In his 1996 patent, Diehl was able to show that cetyl myristoleate was effective in largely curing *osteoarthritis* in humans. He gave six examples of outstanding therapeutic success (it had already worked for him) with different types of delivery. In three of these example cases, the cetyl myristoleate was administered orally, in one case by injection, and in two cases topically. As we will discuss shortly, according to the details given in his six

examples the different forms of delivery were effective in far lower doses than he had used and recommended for rats.

There are two curious things about all Diehl's patents. He seems to have engaged a bad lawyer, because, in the first place, there are some strange typographical errors, e.g. 0.75 often appears when it is obvious that 0.075 is intended. In the second place, it is quite a feature of the 1996 patent that the "therapeutically effective dose" is said to lie in the fairly narrow range of 350 to 375 parts per million. Diehl did not put it quite like that, but 350 parts per million (ppm) is perhaps easier to grasp than 0.035%, and certainly easier than the 0.05 gm per 140 gm of body weight (such is the advice rendered in the patent, with rats in mind). Note that the 350 parts per million refers to parts of cetyl myristoleate per parts of body weight. Thus one might say 'ppm by weight', but from now on, we can take that as understood. It should help to convey a sense of scale to note that, in the case of a 70 kg (154 lb) person, 350 ppm indicates about 24 grams of cetyl myristoleate.

In curious contradiction to this recommended minimum concentration of 350 ppm, the six examples that Diehl quotes, in the 1996 patent, relate to the use of approximately 70 ppm orally, 25 ppm for delivery by injection, and 15 ppm when applied topically. Exactly why the patent is so poorly drafted must be somewhat speculative. I will put those speculations in endnote 3.

The low concentration is significant for the scam part of the story, but before proceeding with that, let us note that Harry Diehl had for long been attempting to interest pharmaceutical companies in his patents, but without success — probably because they could not see anything that they could securely patent. That is where the research ends, and the scams begin!

### **The San Diego Clinic scam**

The late Dr. Len Sands, director of the San Diego Clinic (subsequently renamed the San Diego International Immunological Center),<sup>(4)</sup> wrote a book titled *Arthritis Defeated at Last*. I have not seen that book, which is now out of print, but I have read a book which is nominally by Len Sands (half written in the first person and half in the third person) titled *Arthritis Beaten Today!* The case histories presented are very convincing.<sup>(5)</sup> They recount almost magical, curative properties of the substance that was being used, but what Sands wrote about the substance being used was wildly misleading. He must have assumed, probably correctly, that the average person is not going to read Diehl's patents. So while, as an extra precaution, he avoided mentioning Diehl by name, he proclaimed that although this "research chemist" had found that cetyl myristoleate worked well *when injected*, it was not suitable for taking orally, as it had a low bioavailability. That problem, he said, had been resolved by the brilliant chemists at the San Diego Laboratory, who had found a way to make the cetyl myristoleate ideally suitable for oral administration.

Sands called this 'wonderful' substance CMO.<sup>(6)</sup> He indicated that the substance was merely a "waxy," highly bioavailable form of cetyl myristoleate, but other than that, he divulged nothing about it. His best advice to those who sought to be sure that they were getting the genuine CMO was to ring up the San Diego Clinic, and ask them if that brand was genuine or not! Not a word passed his lips about who was manufacturing it!

Not only was Sands shifty about who was producing this CMO, but also about how much CMO would cost. The sort of answer that he volunteered was, "Not too much when you consider its immense benefits!" According to the PermaHEALTH website,<sup>(7)</sup> in 1996 the cost was \$275 for 50 capsules. When the word got around that this CMO, containing cetyl myristoleate, was having noteworthy success, it is not surprising that other firms jumped on the band wagon, and gave the name "CMO" to anything that they produced with a

smidgeon of cetyl myristoleate in it. Oddly enough, they somehow managed to price it at considerably less than \$275 for 50 capsules! The price is now about 7% of that.

Eventually those who were producing CMO according to the San Diego Clinic recipe could no longer resist this competition from unspecified variant forms of CMO, so they had to declare themselves to be the original producers of the San Diego Clinic formulation, and state what that formulation was. It turned out that CMO — San Diego Clinic style — contained only 8.2% cetyl myristoleate! <sup>{8}</sup>

So much is straight fact. Now we have to move into an area of conjecture, as to why it was thought financially advantageous to dupe the public in this way. As we have seen, Diehl recommended a “therapeutically effective dose” of 350 to 375 ppm. It would be infringing Diehl’s patent to produce capsules offering that dose. On the other hand, 50 capsules of the approved San Diego Clinic formulation were being sold with 385 mg (milligrams) of the mysterious CMO, per capsule. At 8.2% concentration, this calculates as 32 mg of cetyl myristoleate per capsule, amounting to 1.6 gm per bottle. For a 70 kg person, that dose amounts to 23 ppm. It was obvious, as we have seen above from a careful reading of Diehl’s 1996 patent, that even this low dose was likely to have some beneficial therapeutic effect. Moreover, since the remaining 92% of the CMO capsules consisted of other cetyl esters of fatty acids, it could be claimed that it was these other cetyl esters that were doing the job, and that a mere 8.2% of cetyl myristoleate was irrelevant to the success of San Diego Clinic’s wonderful product! So San Diego Clinic, and the manufacturers that they were using, were fireproof against being sued for infringing patent rights. What is more, the low cetyl myristoleate content of 50 capsules, 1.6 grams, might well make people come back for more. Perfect marketing!

### **The curious case of EHP Products Ltd**

With so much scamming going on, it is hard to know whom to put any faith in. EHP Products Ltd claim to be the true inheritors of Harry Diehl’s patent, and to have had his approval for their product Myristin®. EHP, at <http://cetylmyristoleate.com>, <sup>{9}</sup> displays a rather poor quality facsimile of an analysis of the fatty acids in Myristin® capsules. The analysis shows 40% myristoleic acid. That suggests that the capsules contain 40% cetyl myristoleate. There are however two puzzles which the owners of the site refuse to address. The capsules contain 650 mg of cetyl esters of fatty acids. 40% of that is 260 mg. So it would seem justifiable for EHP to claim 40% *cetyl myristoleate*. However, their main claim on their website is for 260 mg of CMO. When asked about this they state that when they use the word CMO it stands for cetyl myristoleate. This is so obviously confusing to the public that one cannot but wonder if they are trying to hide something. But this seems not to be the case, for when I bought a bottle of capsules the contents were listed with perfect clarity, showing that a 650 mg capsule of CMO contains:

	<u>mg</u>
Cetyl myristoleate	260
Cetyl oleate	238
Cetyl myristate	63
Cetyl linoleate	39
Cetyl palmitate	20
Cetyl laurate	16
Cetyl esters	<u>14</u>
Total	650

The cream is similarly forthcoming about its contents:

Cetyl myristoleate (5%)	
Cetyl oleate	PEG-12 glyceryl
Cetyl myristate	Distearate
Cetyl linoleate	PEG-100 stearate
Cetyl palmitate	Glyceryl stearate
Cetyl laurate	Glycerin
Cetyl palmitoleate	Benzyl alcohol
Cetyl stearate	Lecithin
Menthol	Tocopheryl acetate
Water	Peppermint oil
Ammonium acryloyldimethyltaurate/vp copolymer	

So that finding out the exact contents seems to be only a problem until the stuff is purchased. Moreover both capsules and cream are very good value in terms of their cetyl myristoleate content. But a suspicious mind might wonder why the website suggests that, “Four bottles of Myristin® and four bottles of Myrist-Aid are required for two months of use.” For just one of their bottles, containing 51 capsules (selling for \$70), would contain 13 gm of cetyl myristoleate, amounting to a dose, for a 70 kg person, of about 290 ppm. So even 2 bottles would take one past the range of Harry Diehl’s 350-375 ppm.

That puzzle is unresolved and another one remains. Since Harry Diehl recommended producing pure cetyl myristoleate, while merely choosing a suitable vehicle to deliver it,<sup>{2}</sup> what caused EHP Products Ltd to produce capsules with only 40% cetyl myristoleate? Unfortunately they will not address that question either. Thus I had my suspicions about this product when setting out on my investigation, but mitigating those suspicions was the fact that I had read a report by a vet which had a considerable ring of truth about it, having treated some 21 animals with Myristin®, with impressive results.<sup>{10}</sup>

### **Where to go for some honesty**

Anyone researching cetyl myristoleate will come across the name of Dr Charles Cochran, who is clearly very knowledgeable about most aspects of nutrition. For a long time he has been extolling the benefits of cetyl myristoleate, which he puts above even glucosamine as a vital component to preserve good joints. He has played a significant part in pointing out the meaningless of “CMO,” and has had several brands of CMO analysed, and then made public the very low cetyl myristoleate content of products sold under the CMO flag.

It seems (from various assertions on the web) that for a long time Cochran recommended a product CetylPure, produced by Natrol. While this appeared to be far less expensive than the various CMO products available, the product was always advertised in terms of the total content of cetylated fatty acids, without specification of the cetyl myristoleate content (and the content was hard to find out). Then Cochran became very enthusiastic about a brand Collastin, even to the extent of writing a booklet, *At Last Collastin*. There were claims for a high cetyl myristoleate content, but they were never to be found where the product was to be bought, which gave rise to some doubts about Cochran’s overt dedication to openness.

The doubts continue with his own website <[www.myjointhealth.com](http://www.myjointhealth.com)>. It apparently shows precisely the contents of the capsules of his Serious Joint Compound. It is stated that the capsules contain 125 mg of “CM complex.” It was not absolutely clear how much cetyl myristoleate the capsules contained, so it seems that Cochran had lost some of his

enthusiasm for the substance. All the links to Cochran produce no response which was not encouraging either, and the vendors are effectively an “order only” set up.

Initially in my CMO experiment, I thought that the CMO from CMO Distribution Centers of America<sup>{11}</sup> was the most trustworthy, so that was what I used. I now think that Myristin, from EHP Products is probably better, but evidence for that is weak.

In conclusion, there is some honesty around, but it is hard work to find it! Some independent evidence for the efficacy of cetyl myristoleate is to be found at the RemedyFind<sup>{12}</sup> website, but it is anecdotal evidence. Somewhat less anecdotal is that available at the impressive site of the Global Institute for Integrative Medicine<sup>{13}</sup>.

### Endnotes

1. AndrewRBFerguson@hotmail.com Tel. (01491) 574850. 11 Harcourt Close, Henley-on-Thames, RG9 1UZ. UK. I am a retired airline pilot, 68 years old, and with no vested interest in cetyl myristoleate other than my search for a palliative for my sarcoidosis. I would be glad to get details of both successes and failures from those who pursue this study, trying various brands to help their arthritis. Remember though that a report is merely anecdotal unless I know that a test is going to be carried out.
2. This detail from Diehl's 1978 patent is of interest: “When administered orally the cetyl myristoleate may be administered in the pure state or preferably with known pharmaceutically acceptable vehicles or solvents such as Tracanth-Acacia, an emulphor-system such as is described in J. Pharm. Pharmacol., 25:344-345 (1973), propylene glycol or a vegetable oil such as corn or peanut oil. The relative proportions of vehicle and cetyl myristoleate are not critical.”
3. In assessing Harry Diehl's patents, it is necessary to recall that they were a protracted effort by him to bring his discovery to public attention. He appeared to rather give up after taking out the 1977 and 1978 patents, after finding that he could not interest pharmaceutical companies. That abandonment of the project seems to have lasted until he cured himself of osteoarthritis in 1991. His doctor, amazed by the success, offered to help him get an academic paper about his experiments published. The article was published in 1994. In the meantime, by now in his eighties, it seems likely that Diehl had been carrying out experiments with friends, also suffering from osteoarthritis. These were so successful, that he decided that he must try to bring this to public attention, and thought that a patent may be the best way to do so, and might help to get a pharmaceutical company interested. He engaged a lawyer, whom it seems reasonable to suppose was doubtful about the possibility of writing a secure patent (probably correctly), but knowing that Harry Diehl's purpose was mainly to bring the success to public attention, he decided to humour him and earn some money in the bargain, by dashing off a patent (as a final part of the previous patents) that at least recorded some of the outstanding successes that Harry Diehl's test had achieved with osteoarthritis (when delivering cetyl myristoleate by injection, orally, and topically). Since, at this late stage in his life, Harry Diehl was not really concerned about making money, he just left it up to the lawyer. That, to my mind, is the most likely explanation for the very poorly written patent.
4. There still exists a CMO vendor at <http://www.sandiegoclinic.info/index.html> with the San Diego Clinic name, but it has no connection with any clinic. There also exists a clinic named the San Diego Clinic, but it has no interest in CMO.
5. Sands gives many case histories, but these may be selected cases. More convincing is a supposed clinical trial with 48 people, in which great success was recorded with all except two, and the failure there was attributed to poorly functioning livers. The trial

is recorded in detail at <http://www.cis9.com/report2.html>. However, apart from the fact that it was conducted by Dr. Len Sands, PhD, and that it was “An informal human study undertaken at a facility called the San Diego Clinic in late 1995,” no further details are available about those involved. As Jim Duguid, professor emeritus of microbiology, observed to me, it thus deserves little credence.

6. EHP Products say that they coined the acronym CMO before Sands, but with them the intended meaning was merely cetyl myristoleate. I have not been able to ascertain the truth of this, but what is certain is that none of the products on the market being sold as CMO contain more than 40% cetyl myristoleate.
7. One of the three PermaHEALTH web sites is at [www.bestCMO.com](http://www.bestCMO.com). This information, about early pricing, is on page <http://www.bestcmo.com/cmo-who-we-are.html> (accessed in February 2006). The other sites are at <http://www.authenticcmo.com/> and <http://www.cis9.com/>. PermaHEALTH describe the last as being their “information site.” The benefits of selling CMO are well illustrated by this quotation: “Our company, Nutritional Health Services LLC, was originally set up 14 years ago as a company for nutritional consultations generated primarily by MD referrals. However, due to the overwhelming response to our CMO product line, the company focus has shifted to managing our web generated nutrition marketing business.” <http://www.bestcmo.com/cmo-affiliate-program.html> (accessed March 2006).
8. The content of “original” CMO is given on the site of CMO Distribution Centers of America at <http://216.92.177.64/labreport.html> (accessed March 2006). This firm claims to have been the one that developed CMO with Len Sands and the San Diego Clinic. The same “original CMO analysis” appears on the site of Natural Products Center (<http://cmorelief.com>), with the analysis being available at the precise address of <http://cmorelief.com/analysis.html> (accessed March 2006).
9. The actual certificate is at <http://cetylmyristoleate.com/certificate1.htm>. EHP Products Ltd have precisely the same website as cetylmyristoleate.com at <http://www.harrywdiehl.com/>.
10. The veterinary report, on treating horses and dogs, is available at <http://downlinebuilders.net/rusty/cetyl-myristoleate/cetyl-myristoleate-vet.htm>, the source being an article in the Journal of the American Holistic Veterinary Medical Association, dated 31 July 1999, titled *Use of Cetyl Myristoleate for Arthritis and Tendonitis in Holistic Veterinary Medical Practice*, by Debra Tibbits.
11. Web addresses for CMO Distribution Centers of America are <http://www.cmocart.com> or <http://www.cmoonline.com>. The price per 2 oz (56 g) pot is \$19, but the cost of shipping to Europe is \$36. Although the shipping cost remains the same for large numbers of the item, significantly larger orders will probably incur VAT and customs charges.
12. The idea of the RemedyFind website, (it is at [www.RemedyFind.com](http://www.RemedyFind.com)), is to share knowledge about what works and what doesn’t work as medicine for almost every variant of human ill. It appears to be a genuine altruistic effort to sort out the wheat from the chaff. This site may not be operative now in the near future. It appears to be undergoing changes.
13. *The Global Information Hub for Integrated Medicine* is the most authoritative, *but still not well informed*, site for information about CM and CMO. It is to be found at: [www.Globinmed.com](http://www.Globinmed.com) Look under Professional, monographs, then choose “Cetyl myristoleate ( CM and CMO).”

## Andrew's Story

In retrospect, it seems probable that my sarcoidosis started about 27 years ago, at the age of about 42. I came back from a holiday abroad with what appeared to be an unusually mild case of flu. At least it was mild in respect of some of the symptoms normally associated with flu, but I was amazed at how tired I felt, having to go to bed a couple of hours earlier than I was accustomed to. Also I soon noticed that I was suffering a loss of short term memory, and that my eyes were often dry. I went to see an optician about the latter problem. He said that some types of flu affect the tear ducts, and he recommended that I use Hypromellose eye drops as a palliative. After about two years the eye problem appeared to go away.

As far as I recall, it took nearly as long for the tiredness to disappear, and it was many months before I regained my normal short term memory. The change in short term memory was fairly subtle, but I recall that for a while I had to write down where I had left my car in the car park before going off for a nightstop, or even a long day trip, whereas previously, and later, I hardly gave a thought to forgetting, after making a mental note at the time.

It was not long after that apparent recovery that I started being troubled not only by a discomfort in my back, but a feeling of malaise that often accompanied it. The malaise was the chief reason that I took an opportunity for early retirement from flying, at the young age of 46. One needs to be feeling fully fit to fly aeroplanes.

Over the next twenty years, the association between back discomfort and feeling of malaise grew stronger. Moreover the malaise itself became far more striking. During the last several years, I would on occasions sit in a chair and marvel at the extent of it! My head felt as though it was full of treacle, and I felt so tired that even listening to music was too much effort. I just sat there like a zombie, waiting for the feeling to go away.

One of the most troublesome things is that I could never predict when bad periods would come, so if someone asked me to do something, even the next day, I had to say that it would depend on how I felt, or when I accepted an invitation some time ahead, I would then start worrying that when the day came I would be feeling ill. I had already told my GP about the malaise accompanying my back problems. Understandably this did not suggest anything to him, he just thought it was a rather unusual side effect of my back problem (which had been investigated, and a somewhat unstable spine was noted).

Then in the year 2000, six years ago, I was helping to plant some saplings. The work was not heavy but at the end of it I felt quite unwell. This encouraged me to see my GP. He thought that I had better have a thorough check to see that my heart was operating OK. The check was certainly thorough. I had a CT scan, a blood test, a 'treadmill' test during which my pulse was monitored, an ultrasound heart scan, and finally I wore a device for twenty-four hours to keep a record of the behaviour of my heart.

The radiologist, after taking a look at the CT scan, and noting the calcium spots on the lungs, said that sarcoidosis was the likely diagnosis. There was almost nothing wrong with my heart. During the treadmill test the nurses noted that I got unusually out of breath. That was something that I had noticed myself for some time, but not thought a great deal about it, except to wonder why I was getting old rather too soon. The consultant said that sarcoidosis was the most probable diagnosis. He wanted to do a biopsy to confirm it, but I decided that I was prepared to accept the evidence thus far, without invasive tests.

Also the consultant wanted me to go back for regular checks, but my GP shared the view that I had already formed, that as the treatments for sarcoidosis were fraught with

problems, it was best to wait until things became sufficiently bad that it was seriously impairing my quality of life, and something really had to be done about it. We still thought that the only clear effects of the sarcoidosis was the shortness of breath and consequent limitation on the amount of exercise I could undertake.

By the end of 2003, even when walking on the level, I had hardly enough breath to both walk and converse. It was clear that something had to be done. At this stage I was also finding that the feeling of malaise was overtaking me nearly every day — for some obscure reason always shortly after breakfast (omitting breakfast made no difference). It was arranged that I should see a consultant, but while I was waiting for the appointment, I tried rubbing an NSAID (Non-steroidal Anti-inflammatory Drug), Voltarol Emulgel P (diclofenac), onto my chest, and found a fairly dramatic improvement. Within couple of weeks, my lung function had improved by 60%. One is not supposed to use the ointment for longer than two weeks (although on occasions I used it for several weeks to establish that it produced no further improvement). After stopping using the gel, lung function deteriorated, until after 17 weeks things were back where I started. I repeated this experiment for five cycles, but at the fourth cycle there was a change: I could only achieve a 40% improvement and the improvement was lost in 7 weeks. On the fifth cycle, the drop off, after I ceased using the gel, back to the starting point, occurred in a mere couple of weeks. I should also say that by this time my persistent cough, which both my GP and I suspected was due to sarcoidosis, had continued for nearly a year.

I was contemplating going to the consultant and starting on the dreaded corticosteroids, when a friend came to my rescue! She had been browsing the internet to find out about sarcoidosis, and had found a substance which was primarily developed and studied as being effective against arthritis, but which apparently had also been successful with various diseases with an autoimmune component, including sarcoidosis. The substance goes by the letters CMO. It is comprised of a mixture of cetylated fatty acids. It is probably the cetyl myristoleate that is the effective component. The efficacy of the substance was discovered by a highly respected chemist in the National Institutes of Health, but the way it has been sold is highly suggestive of a massive scam. Nevertheless there is convincing evidence of its efficacy, so I decided to give it a try.

Thus, on 18th March 2006, at the age of 68, I started to use CMO. In order to make a comparison with the diclofenac gel I had been using, I decided to start with CMO cream.

I could monitor my progress in a way that I had now developed to a high degree. I measured how many steps I could take per respiration cycle when walking on level ground over a distance of about 1000 metres. Over a distance of that length, one really cannot 'cheat', since *time* is also an element of the assessment, and with shorter steps it takes a longer time to cover the distance.

14 days after starting using CMO cream, the improvement in lung function, though rapid, had peaked out at a 40% improvement. Then I stopped using CMO, and within a week, lung function had returned to the starting point (of 5 steps per respiration cycle). This would have been disappointing except that other dramatic improvements had occurred. By the end of the two weeks of treatment, the feeling of fatigue, which I nicknamed Totally Erratic Exhaustion Syndrome (TEES), had disappeared entirely. Moreover there was what I judged to be only 20% left of my persistent cough. With somewhat less confidence, because of the difficulty of assessment, I reckoned that there had also been a 30% improvement in my dry eye problem.

At the end of the three weeks that had now elapsed, I started on a bottle of CMO capsules. Within two days I had regained the 40% loss of lung function. This very rapid improvement was probably a result of the *amount* of cetyl myristoleate used rather than the

fact that I was now taking capsules. The cream contains only 0.6 grams of cetyl myristoleate, whereas the bottle of capsules contains about 2.3 grams. After achieving this 40% improvement, there was no further improvement over the rest of the two weeks that I was taking the capsules. However on this occasion, after I stopped taking the capsules there was no drop off at all in lung function.

Indeed, gradually, if somewhat erratically, over the next 3 months lung function improved to a peak of 110% improvement (that is to say I could manage 10.7 steps per respiration cycle instead of 5. For some of this time I had been using very small amounts of CMO cream, and for a while one capsule every other day. For several weeks I used none at all; yet broadly speaking the slow improvement continued throughout.

However, when the peak had been achieved, and I stopped using any CMO, the lung function dropped back over the next two weeks to only a 60% improvement. But then for the next 20 weeks, using very little CMO, lung function maintained an average improvement, compared to the start, of 70%.

During November, 2006, I had a big boost to my confidence regarding the stability of the improvement. On 13th November, I succumbed to a moderately bad cold/flu type germ. That is one thing I really dreaded because, when the sarcoidosis was active, a cold would turn into a dreadful cough (sometimes I thought I was going to expire because of difficulty in stopping coughing for long enough to draw in any air), and the cough would take months to go away (I went through that twice). However, on this most recent occasion, the cough only returned slightly, at one time to the extent that my assessment was of an improvement rating of only 70%. During December 2006 I have been rating it at around a 90% to 100% improvement. The TEES made only fleeting reappearances, and it was fairly slight in nature. TEES incidentally is distinguishable from just feeling fatigued, because it is accompanied by a discomfort in the lumbar region of the spine.

There is much more detail that I could give, as I have graphs of the changes in lung function. The dramatic improvement in my dry eye problem would be worth a few paragraphs. Moreover the story is still unfolding. I will go on monitoring changes in lung function for at least 20, and perhaps even 60 weeks. The extent to which lung function might return to normal is uncertain, but it would be odd if I did not get back to the 110% improvement that I achieved at one time.

What is certainly the case is that the success so far — with a long term chronic lung malfunction in which the diagnosis was sarcoidosis — should encourage others to try the same. CMO is sold as a food supplement or topical cream, and has no detrimental side effects, except it has been observed to cause a temporary worsening of symptoms (particularly when used to treat arthritis) before the improvement. The most authoritative site on CMO does not mention sarcoidosis, but it is worth looking at. It can be located at <http://globinmed.com>; then on the left side, under “Professional,” click on “Dietary Supplement Monographs,” and from the list choose “Cetylmyristoleate (CM & CMO).” If you want to contact me directly, please do so:

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Tel: (01491) 574850; AndrewRBFerguson@hotmail.com

As is apparent from the text, Dave sent us this story in mid 2006. It would be nice to have been able to update it with what has happened since, but he has not replied to our enquiries. As it stands it does at least provide some indication of the trials and tribulations of those who suffer from the protean symptoms of sarcoidosis, which it often takes doctors a long while to diagnose.

### **Dave's Story – Part 1**

I am 28 years old from Glasgow and I was diagnosed with Sarcoid in Feb/March of 2006. I initially went to my GP about large lumps in my neck and chest/lungs and she immediately told me it was likely I had Hodgkin's Lymphoma; obviously I was very shocked and upset. I was sent off for tests. I had blood tests, x-rays, CT scans, needle biopsy, core biopsy and lymph node removal under a general. I was told throughout I had cancer and Chemo or Radiation therapy would be used. They then got the results of the lymph node removal and found granulomas.

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

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

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

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

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

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

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

### GA's Story

1. I was diagnosed with sarcoidosis of the lungs in 1974 after a bronchoscopy and Kveim test, following a previous misdiagnosis of TB.
2. Once I was taken to hospital with the diagnosis of a heart attack. After five days in hospital the doctors realised again that this was a misdiagnosis and that it was sarcoidosis of the heart.
3. Also I now have a lot of trouble with both lungs due to an asbestos related disease.
4. Steroids were used over a very long period of time resulting in many side effects.
5. We have very few chest consultants in the UK, or GPs who understand sarcoidosis, yet the USA has many and good web-sites with regard to sarcoidosis.

I have now joint and mobility problems. Is this sarcoidosis? After many tests nobody seems to know.

So, based on my own experience, if you are ill and diagnosed with sarcoidosis make sure that you tell all, plus try and find out from your local hospital if there is a consultant physician who knows about sarcoidosis.

I only know from my past and present experiences with sarcoidosis and hope that these will be of some help.

Mr. G.A.

**Editorial comment.** GA's comments bring out many typical aspects of sarcoidosis and its diagnosis. In the first place, shadowing in lung x-rays is apparent in both TB and in sarcoidosis. Further tests are necessary to distinguish which it is.

In the November 2006 issue of the Journal of the American Medical Association (JAMA), there was an article on sarcoidosis which finished with the author, Dr Steven Weinberger, responding to questions put by other doctors. One of them was, "What has happened to the Kveim test?" This is an extract from Dr Weinberger's response:

The Kveim test is an intradermal skin test that uses a suspension of ground-up spleen from a patient with sarcoidosis. The test site is biopsied after 4 to 6 weeks, and the finding of non-caseating granulomas at the test site represents a positive response. ... At present, standardized test material is not readily available and should only be used with special Food and Drug Administration approval.

The Kveim test has always been of dubious value, as it is only indicative anyhow, and it seems from what Weinberger says that it unlikely to be available anyhow.

It is unsurprising that no one is sure if GA's joint and mobility problems are due to sarcoidosis. One of the strange things about sarcoidosis is that it manifests with different symptoms in different people. Joint problems are not infrequent. One of the links that is available on the home page of [www.sarcoidcenter.com](http://www.sarcoidcenter.com) is "Organ involvement." From the table there, evidently joints are an aspect of sarcoidosis in 25-50% of cases.

From item 2 of GA's story, it would appear that his sarcoidosis is affecting his heart. Perhaps the doctors are sure of that now, but it is a symptom in only 5% of cases. Thus it is never easy to be sure what is and what is not sarcoidosis. The problem is surely enhanced in GA's case by the additional problem of asbestosis.

All **Correspondence** and **leaflet requests** (please enclose a stamped and addressed envelope for a reply together with four first class stamps) should be addressed to:

The Secretary, SILA  
c/o The Chest Clinic Office  
2nd Floor Admin Block  
Kings College Hospital  
Denmark Hill  
London SE5 9RS



**Support Meetings** are held at the above venue on the first Thursday of each month with the exception of August. Meetings are now planned to be held in The Ferguson Room (instead of the Belgrave Room) but if this is found not to be the case, then enquire at the Help Desk or Security Window, near the main entrance, ground floor, for the location of the meeting. Meetings are held between 7 pm and 9 pm.

**Electronic version of the SILA newsletter:** The newsletter is prepared in Word. If anyone would like to receive an electronic copy, please contact the guest editor directly, AndrewRBFerguson@hotmail.com. If you are sufficiently happy with the electronic form, then you may decide to forsake the hardcopy altogether, but it will not be withdrawn without your say so.

**Information received:** The aim of the multilingual Orphanet Database is to contribute to the improvement of the diagnosis, care and treatment of patients with rare conditions. The database is available to the general public. SILA has been added to this database, the general purpose of which is to provide a Europe-wide database of rare diseases and orphan drugs. The web address is [www.orpha.net](http://www.orpha.net) In the UK it is led by Professor Dian Donnel. To find out more contact:

Kate Strong, Project/Research Support Assistant  
North West Genetics Knowledge Park (Nowgen)  
29 Grafton Street  
Manchester M13 9WU Tel: 0161 276 5966 (ext., 3830)

and also Dr.Emma Gillespy ([emma.gillaspy@cmmc.nhs.uk](mailto:emma.gillaspy@cmmc.nhs.uk)) 0161 276 3203

**The Irish sarcoidosis support group.** This is to be found at [www.isarc.ie](http://www.isarc.ie), email address is [info@sarc.ie](mailto:info@sarc.ie). Physical address is Gurtaqcur, Mount Bolus.Tullamore. C.Offaly. We are in contact with Mary Walters, chair of ISARC about the vexed question of “incidence” and “prevalence” of sarcoidosis in Ireland. There is uncertainty about the figures that are currently available. Often there is a lack of clarity about whether it is incidence or prevalence that is being referred to. The definitions, of these terms, as given by the Sarcoid Center, [www.sarcoidcenter.com](http://www.sarcoidcenter.com), are these:

**Incidence:** The number of new cases that occur during a given period of time, e.g. 100 cases/100,000 population /per year.This is the rate of occurrence of the disease.

**Prevalence:** The number of cases that exist at a given point in time, e.g. 100 cases/100,000 population in 2007. This is the proportion of the population that has the disease.

Mary Walters tells us that Dr Seamas Donnelly, who has a specific interest in the research and treatment of sarcoidosis and was instrumental in setting up ISARC, is going to attempt to give some clarification of the available figures at the next support meeting.

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

Our website can be found at [www.sila.org](http://www.sila.org); the email address is [info@sil.org](mailto:info@sil.org)