

**AN INTERIM REPORT — TWO YEARS INTO THE EXPERIMENT —
ON TREATING MY CHRONIC SARCOIDOSIS WITH CETYL MYRISTOLEATE**

Written by Andrew R.B. Ferguson

SECTION 1 - INTRODUCTION

This is a report by a SILA member. As of last Friday, 12th January 2007, I was 43 weeks into my currently successful experiment of treating my chronic sarcoidosis with the non-harmful substance cetyl myristoleate (contained in CMO cream and CMO capsules). Prior to that, I experimented for fifteen months with the Non Steroidal Anti-inflammatory Drug (NSAID) Voltarol Emulgel P. That gel had intermittently short-term beneficial effects on lung function. While overall it was not a success, that part of the experiment enables the more lasting success of treatment with CMO to be seen within a wider perspective. With that in mind, I am effectively two years into the experiment.

An article on sarcoidosis in the *Journal of the American Medical Association* (JAMA), November 2006 issue, encouraged me — with the help of a friendly doctor who found my experience interesting — to write a 400 word letter to JAMA. We put considerable effort into compacting the essence of the story into 400 words. See Section 2 (p. 2) below for that brief account.

Obviously much is left unsaid in 400 words, so a more comprehensive report, titled *Sarcoidosis and the Rosetta Stone*, is made available in the final section, Section 3 (p. 3) of this report.

This is an interim report because I intend to continue for another 60 weeks, but I would be glad to help others start down a similar path of experiment without delay.

SECTION 2: 400 WORD LETTER TO THE JAMA

Clinical Crossroads: A Case of Sarcoidosis

To the Editor: The *Crossroads* report on a case of sarcoidosis by Dr Weinberger¹ confirmed that the medical profession does not know what causes sarcoidosis, and that the effectiveness of all available palliatives is disputed. What is not in doubt is that their side effects can be dire. Thus one may ask for serious consideration to be given to any reliable evidence that a particular substance will significantly alter the course of sarcoidosis. I describe my personal experience of chronic sarcoidosis and suggest a formal trial of cetyl myristoleate (contained in CMO).² It has been tested on inflammatory arthritis.³

Once my sarcoidosis — overtly showing mainly fatigue after exercise and shortness of breath — was diagnosed in 2000 (without biopsy but with a raft of tests including CT scan), it was evident that it had started 25 years previously. Latterly, the worst aspect was what I nicknamed TEES (Totally Erratic Exhaustion Syndrome), but by a year ago this was a misnomer as it was no longer erratic — I rarely felt well before about 6pm. The second worst was a persistent unproductive cough; on a bad day rarely ten minutes would pass without an urge to cough. Equally a problem was poor lung function. I felt that I would soon be unable to walk into town and back: I live up a hill and the return journey was already becoming an ordeal.

My experiment with CMO started 41 weeks ago. The early results were that within a week of applying CMO cream to my chest I no longer felt unwell, and my cough was about 80% improved. Despite my seven-times proven immunity to placebos, there could be a psychological element to these changes, so what may be more impressive to a skeptical mind will be the recorded changes in lung function. Within a week, there was a 40% improvement, from 5 steps to 7 per respiration cycle. After another week I stopped using the cream. I lost the improvement within a week. Then I started on CMO capsules. Within 2 days I had regained the lost 40%. Gradually, over the next 20 weeks, and without using much more CMO, my lung function improved by about 110%, from 5 to 10.7 steps per respiration. For the last 18 weeks the improvement has mainly been oscillating between 60% and 80%. Full details of my treatment and progress are available on the website of the Sarcoidosis and Interstitial Lung Association.⁴

Andrew R.B. Ferguson
andrewrbferguson@hotmail.com
 11 Harcourt Close
 Henley-on-Thames
 Oxfordshire. RG9 1UZ, UK

Acknowledgment: I have been greatly helped in my interpretation of measurements of lung function by the advice of Dr John F. Nunn, author of *Nunn's Applied Respiratory Physiology*.

Financial disclosures: None relevant (69 year old retired airline pilot).

Notes

1. Weinberger SE. Analysis of the case of a 47 year-old woman with sarcoidosis in the *Clinical Crossroads* series. *JAMA*, 2006, 296: 2133-2140.
2. Diehl HW, May EL. Cetyl myristoleate isolated from Swiss albino mice: an apparent protective agent against adjuvant arthritis in rats. *J Pharm Sci*, 1994, 83: 296-299.
3. Siemandi H. The effect of cis-9-cetyl myristoleate (CMO) and adjunctive therapy on arthritis and auto-immune disease: a randomised trial. *Townsend Letter for Doctors and Patients*, 1997, Issue #169: 58-63. (the best version available on the web is close to the original printed paper and is at: http://www.rejuvenation-science.com/cmo-research_siemandi.html).
4. Ferguson ARB. Sarcoidosis and the Rosetta stone: a two-year interim report on the effect of cetyl myristoleate (CMO) and other substances on lung function.

SECTION 3: SARCOIDOSIS AND THE ROSETTA STONE: a two year interim report on the effect of cetyl myristoleate (CMO) and other substances on the lung function of Andrew Ferguson.

by Andrew R.B. Ferguson *

Abstract

This *interim* report by a member of SILA (Sarcoidosis and Interstitial Lung Association), in January 2007, is a summary of the writer's own experience over two years of the effects of various "substances" on chronic sarcoidosis. For eighteen months of that time, lung function has been monitored assiduously. Aspirin (225 mg per day) was tried first; it had no effect. For nine months, the effects of the NSAID diclofenac, Voltarol Emulgel P, was accurately monitored. For over a year, it produced substantial intermittent improvements in lung function, but at the end of that time the degree of improvement was of little use. For the remaining nine months, cetyl myristoleate (contained in CMO) was used. This virtually eliminated Chronic Fatigue type symptoms and a persistent cough typical of sarcoidosis. It also improved a dry eye problem by 80%. Lung function improved by 110% at one stage, but over the last 18 weeks, with very little further treatment, it has mainly stabilized at around a 70% improvement. Changes in lung function can be measured easily and accurately. Because of this, although sarcoidosis is a rare disease, it may be the Rosetta stone which uncovers the effect of CMO on inflammatory diseases of unknown origin. In the form in which the "substance" is supplied — CMO topical cream, and CMO capsules sold as a food supplement — it has virtually no risk. The evidence presented here suggests the need for more study of cetyl myristoleate.

If the statistics are to be believed, even in Sweden where sarcoidosis is fairly common, the incidence of sarcoidosis is about 12 per 100,000 per year, and the prevalence is about 64 per 100,000. While this rarity makes the disease difficult to study, sarcoidosis does have one considerable advantage over other similar inflammatory diseases, i.e. those without a known cause or cure such as rheumatoid arthritis. With suitable cases of sarcoidosis — those in which deterioration of lung function has become chronic — the lung situation does not fluctuate from day to day, as does, with say rheumatoid arthritis, the level of discomfort or pain. Moreover it is fairly easy to take an accurate measure of lung function.

I was one of those rare sarcoidosis cases in which impairment of lung function had become chronic, and I have been able to study myself in great detail. If a few others could replicate this study, it may throw light on not only sarcoidosis, but other inflammatory diseases of unknown cause, because the substance with which I have been singularly successful has mainly been demonstrated to be effective (with many difficulties of measurement) in rheumatoid arthritis and psoriatic arthritis. I recount details of my study thus far in the hope that others may be able to help in the objective of replicating my experiment

The November 2006 issue of the Journal of the American Medical Association (JAMA) had an article on sarcoidosis (pp. 2134-2140). It contained many interesting facts, but the bottom line was this: the medical profession does not know the cause of sarcoidosis, and the effectiveness of all the palliatives that are available is in doubt. What is not in doubt is that their side effects are dire. Thus it is surely fair to ask for serious consideration to be

* Andrew R.B. Ferguson (Research Co-ordinator, Optimum Population Trust), 11 Harcourt Close, Henley-on-Thames, Oxfordshire, RG9 1UZ, UK, Tel: (01491) 574850. AndrewRBFerguson@hotmail.com

given to any reliable evidence that a particular substance will significantly alter the course of a case of chronic sarcoidosis.

The imperative for giving further consideration is enhanced by the fact that there is plenty of anecdotal evidence, and some clinical evidence, that the substance is effective in producing substantial improvement in cases of inflammatory arthritis including psoriatic arthritis.¹ What is evident from my investigations is that the substance does not work for everyone, but it does work very well for some people (including those diagnosed with osteoarthritis) and some animals. Indeed some of the most convincing evidence came from a vet, recounting nearly a dozen remarkable cures for arthritic dogs. Now back to myself.

I am now 103 weeks into an extended experiment into curing my sarcoidosis. I currently anticipate the experiment to end after about 2 years into the CMO experiment. Issuing an interim report has the benefit of showing that the rest of the experiment is irrefutably prospective, rather than retrospective. In fact I would argue that since I started the CMO part of the experiment, on 18 March 2006, the experiment has been prospective, because only three days after that, seeing that it was having an effect, I decided to continue the experiment that had begun 14 months previously with testing an NSAID gel.

Since I am recounting the details of only one case, my own, I appreciate the need to replicate my experiment, and would suggest that the minimum requirements for someone attempting to do that is that their sarcoidosis, or the case of sarcoidosis they are investigating, should *definitely* be chronic, primarily pulmonary with severely impaired breathing function, and accompanied by a persistent non-productive cough; ideally these symptoms would also be accompanied by the exhaustion symptoms that are fairly typical of Chronic Fatigue Syndrome; and it would be a bonus if there were to be a problem with dry eyes.

Those requirements, if completely satisfied, would encompass my own condition at the time I started using CMO, although the situation was less severe when, in the year 2000, I underwent a barrage of tests — CT scan, blood test, treadmill test with pulse being monitored, echo cardiogram, and wearing a tape recorder to monitor my heart for 24 hours. The results indicated that my problem was sarcoidosis, and it became clear that the problem had started about 25 years earlier. However I did opt out of a lung biopsy, so the rigorously minded might say that my sarcoidosis was never fully confirmed.

At the beginning of my NSAID test, starting in December 2004 when my lung function on level ground had dropped to about 5 steps per respiration cycle (I could no longer both walk at normal speed and talk), I was at the point of deciding that I would have to see a consultant, and consequently probably start on prednisone. My GP had recommended it was best to wait and watch until the problems were so bad that I felt something *had* to be done; I willingly concurred. I had already tried taking 225 mg of aspirin a day, but that made no difference at all. However, while waiting for my appointment, I tried another experiment. This time I used the NSAID diclofenac diethyl-ammonium (Voltarol Emulgel P). Yes, it was only an experiment, but I wanted to look at a few alternatives before going onto prednisone. Initially, application of the diclofenac to my chest, three times a day, resulted in about a 60% improvement in lung function over about six weeks. The improvement then declined over several months. I went through two of these cycles before deciding that I must start to study the changes in lung function more accurately. Thus Figure 1 shows only the last three Voltarol cycles.

The first cycle shown on Figure 1 is the third cycle of treatment with Voltarol gel. I was beginning to hope that I could always achieve the improvement shown in the first cycle of Fig. 1, which did not seem very different from the two previous non-recorded cycles, but on the next cycle, despite continuing Voltarol use for three weeks after reaching the peak in lung function, I could not achieve more than a 40% improvement. Moreover each time the peak of improvement was achieved, the decline was more rapid.

By 22nd February 2006, I had returned to the low point in my lung function, and there was little point in continuing to test Voltarol, but by great good fortune, months previously a friend had told me about something that she had located on the internet. It may well not work, she said, but it is unlikely to do any harm, so seems worth trying. When I looked into it, the only danger from it was of encountering relatively mild Herxheimer reactions (I did get one of those with respect to my dry eye problem: for a couple of weeks it looked as though someone had hit me in the eye). This substance, my friend told me, is called CMO. Readers need to know more about it than its name.

The active ingredient is a natural compound called cetyl myristoleate. It is found at high concentration (350 mg per kg of body weight) in a certain strain of Swiss albino mice which are immune to adjuvant arthritis (the immunity is no coincidence).² The compound is found in small amounts in whales, beavers, cows and some other animals. It can be synthesized from myristoleic acid, which means that now (after the big scam is largely over) it is not expensive. From one supplier it is about US\$13 for a 56 g pot of 5% cetyl myristoleate cream. A bottle of 51 capsules, containing in total about 4.7 times as much cetyl myristoleate as the cream (13.3 g as compared to 2.8), costs US\$45.

So much for the nature of CMO. Another point is that before my CMO experiment commenced, in March 2005, I had done a couple of months of research into the substance, mainly on the internet, and in the course of it I had come across several anecdotal cases of CMO 'curing' sarcoidosis (although details of treatment were always sparse, and follow up negligible). But better evidence is available for the efficacy of CMO in treating inflammatory arthritis.¹ Moreover the final 1996 patent taken out by Harry Diehl, the chemist who isolated and synthesized cetyl myristoleate, records half a dozen cases of it substantially curing osteoarthritis.³

I need to give more precise details of my condition when I started CMO treatment about 40 weeks ago. The worse aspect of my sarcoidosis was what I had nicknamed TEES (Totally Erratic Exhaustion Syndrome). In fact TEES was by then a misnomer, as it was no longer erratic. I nearly always felt unwell after breakfast and rarely felt well before about 6 pm. The second worst thing was my persistent unproductive cough. On a bad day, I should think that rarely ten minutes would pass without a hard-to-resist urge to cough overcoming me. About equal with that, in terms of being a problem, was poor lung function. It was becoming apparent that soon I would not even be able to walk into town and back. I live up a bit of a hill, and the return journey was already becoming a bit of an ordeal.

The early results of my experiment will take some believing, but the truth is that within a week of applying CMO cream to my chest, I no longer felt unwell, and my cough was about 80% improved. Despite my seven-times proven immunity to placebos, some might say that there could be a psychological element in both of those changes, so what is probably more impressive to a skeptical mind will be the recorded changes in lung function.

Figure 2a shows what happened to my lung function when I started using CMO. I commenced by using the cream. Within a week there was a 40% improvement, from 5 steps to 7 per respiration cycle. After another week I stopped using the cream. I lost the improvement within a week. Then I started on CMO capsules. *Within two days* I had regained the lost 40%. Then gradually, over the next 20 weeks, and without using much more CMO (see Figure 2a), my lung function improved by about 110%, i.e. 10.7 steps per respiration cycle instead of 5. That is very close to normal, but I must stress that those figures can easily be misleading, because 'normal' people of my age, sixty-nine, do not need, as I do with my sarcoidosis, many more steps per respiration cycle when on a slight gradient. I would have to achieve a 200% improvement to be 'normal' on a 1:20 gradient

(the general point is made clear by the two lines in Figure 2b, with ‘normal’ benchmarks shown near the right vertical axis).

One unresolved question is why I reached that 110% peak. For afterwards, I dropped back to a 60% improvement (Figure 2b), and mainly fluctuated thereafter between 60% and 80% improvement. However even a 60% improvement is not to be undervalued — lung function seems fairly normal at 8 steps per respiration cycle unless I am climbing a gradient. Going up two flights of stairs at natural speed is no problem. Moreover taken with the other improvements that are less easily quantified, I have, for the present at least, moved well out of the range of needing help from the medical profession.

It will be noted in Figure 2b that CMO cream produced no benefit when applied for three weeks (end October beginning of November 2006). This was not entirely unexpected, since TEES had disappeared and so had my cough, and the dry eye problem was 80% improved. Thus I had anticipated the possibility that with the sarcoidosis no longer being a problem except for lung function, the body was merely doing, or failing to do, its own repair work on the lungs, in which case the CMO was unlikely to have an effect.

During November, 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.

The story is not finished. The improvement may turn out to be temporary, but anyone who thinks that they are beginning to get a handle on the pathology of sarcoidosis needs to fit into their theory what has happened to me so far. So that is the situation 40 weeks into my CMO experiment. It is suggestive, but certainly requires to be replicated by others.

I have already mentioned the article in JAMA. It was by Dr Steven E. Weinberger. It might be useful to comment on a point he raised, since my investigations are relevant, and one point which may have occurred to readers is to doubt the accuracy of my steps-per-respiration-cycle method of assessing lung function.

On page 2135 Weinberger says, “Fortunately, pulmonary function is relatively preserved in the majority of patients with sarcoidosis, as in the case of Ms K. At the time of presentation, 69% of patients in the ACCESS study had a normal forced vital capacity (FVC) 80% or more of predicted. In contrast, FVC was between 70% and 79% of predicted in 18% of patients, between 50% and 69% in 11% of patients, and below 50% of predicted in only 30% of patients.”

I started in the 11% category, but more significantly, my experience suggests that while FVC provides some indication of overall lung function, it is very far from a complete one. I first had a spirometry test when my lung function was at its nadir, and although I did not make a measurement then, I can be pretty certain that I was down to 5 steps per respiration cycle. I had further spirometry tests done at 7 and 9 steps per respiration. For the owner of the lungs, there is an enormous difference between 5 and 9 steps per respiration cycle. So what did the spirometry tests show? The FVC readings were 67%, 74%, 77% of predicted as normal for age, etc. While that shows improvement, it does not reflect the improvement that occurred in terms of the amount of work that the lungs would allow the body to do. A possibly more telling comparison is that FVC was 2.56 liters at 5 steps and 2.82 at 9 steps.

2.82 is 10% more air than 2.56. But 9 steps per respiration cycle indicates that, at constant lung capacity, only 56% as much air is required to achieve the same result as could previously be achieved at 5 steps, i.e. there has been a 44% improvement in what an intake of breath can do, and we have seen that only a small part can be accounted for by increased lung capacity. I think the conclusion is obvious: other aspects are as relevant as changes in ventilatory function, namely those related to gas exchange and oxygen transport. Measurement of some of these aspects is not clinically available. For those who doubt the consistency of a measurement of steps per respiration cycle, I put more details at endnote⁴.

Unanswered questions. Supposing that my experience is not exceptional, then hypotheses are needed to explain the following observations:

- a) The NSAID Voltarol has a diminishing effectiveness on each cycle of application.
- b) The CMO, once administered in an adequate amount, continues to have a beneficial effect for nine months afterwards (limited to 9 months at this interim stage).
- c) After initial treatment with CMO, improvement in lung function first continues to improve, but then drops back to a lower level, albeit not close to the starting point.

It is not difficult to make speculative hypotheses that would explain all those observations, but the first task must be to confirm that other patients follow similar patterns.

Conclusion. It is possible that I am an exceptional case, but as the first person to take a quantitative look at the effects of CMO on sarcoidosis, it is unlikely that I am the most successful case that will ever be encountered. Since CMO is not expensive, and neither is it dangerous (it is sold as a topical cream and food supplement), it would seem incumbent upon those studying sarcoidosis to take every opportunity to investigate it further.* Moreover this experience, supposing it is not unique, is surely one which those working at comprehending sarcoidosis should try to accommodate into their understanding of the disease.

Acknowledgment. I would not have been so confident in my interpretation of measurements of lung function had I not benefited from a great deal of helpful advice from Dr John F. Nunn, author of *Nunn's Applied Respiratory Physiology*.

* There is a problem in choosing CMO suppliers. I used cream and capsules from CMO Distribution Centers of America (www.cmocart.com/) for the experiment on myself, but I now tend to think that the cream and capsules sold by EHP Products Ltd (trademark Myristin, www.cetylmyristoleate.com) are both more effective and better value (it was their prices which were quoted above). My view of the matter rests on the fact there is about five times as much cetyl myristoleate in the Myristin products, and also on the grounds of some notable successes using Myristin cream in helping people with their arthritis and similar problems. I have not met a suitable case of sarcoidosis so as to be able to extend my sarcoidosis trial.

Whichever vendor is chosen, remember that the FDA proscribes any reference to effective treatment of disease unless a product has been rigorously tested, so reading the information on the websites will give no more than the occasional clue as to the anti-arthritic properties of cetyl myristoleate. Moreover, for historical reasons (as far as I can see) even CMO websites allow confusion between the meaning of CMO and cetyl myristoleate (also sometimes designated CM). Cetyl myristoleate is only a component of CMO, CMO being mainly a collection of cetylated fatty acids (with a variety of other ingredients in the creams). Both the sites mentioned show an analysis of their product, and the Myristin cream pot is very detailed about its contents.

There is one further point of relevance for those who wish to make further enquiries. About the only unbiased commentary on CM and CMO is to be found at www.globinmed.com (look under Professional, monographs, then choose "Cetyl myristoleate (CM and CMO)"). The monograph is far from comprehensive, and does not refer to sarcoidosis.

ENDNOTES

1. Siemandi, H. 1997. The Effect of cis-9-Cetyl Myristoleate (CMO) and Adjunctive Therapy on Arthritis and Auto-Immune Disease: a Randomized Trial, *Townsend Letter for Doctors and Patients*, 1997, Issue #169, pp. 58-63. The best, but not perfect, electronic copy is at http://www.rejuvenation-science.com/cmo-research_siemandi.html

2. Diehl HW, May EL. Cetyl myristoleate isolated from Swiss albino mice: an apparent protective agent against adjuvant arthritis in rats. *Journal of Pharmaceutical Sciences*. 1994 Mar, 83:3,296-99.

3. Diehl's 1996 patent, number 5,569,676 can be located at www.uspto.gov/patft/index.html

4. **Steps per respiration cycle** are measured over a distance of about 1000 metres. Time is as important as the number of steps, since obviously the faster one goes the more work is being done (one must also take care that there is not much wind). My standard time is 9 minutes 52 seconds (6.1 km/h or 3.8 mph). It does not matter if I do, for example, 7 steps per respiration cycle in 9 mins 52 seconds or 8 steps in 11 minutes 32 seconds (5.2 km/h or 3.2 mph). Either would count as 7 steps per respiration cycle, because I have found that I can manage an extra step at a cost in time of 100 seconds, i.e. each 10 seconds is equal to one tenth of a step per respiration cycle. Thus the extra 100 seconds, between the two times shown above, corrects the 8 steps to 7 steps.

Some people have suggested that one could 'cheat' by taking shorter steps, but that is not the case. One is indeed forced to take shorter steps on those occasions that there is just not enough air to manage the intended number of steps, but the consequence of taking shorter steps is to take a longer time.

I was initially concerned that my heart rate would go very high while trying to make do with insufficient oxygen, so I wear a heart monitor, and slow down if my heart rate goes above 110 beats per minute. For some reason, during the course of the experiment there has been less tendency for that to happen, and hence for me to slow down. I think that in fact the test would still be accurate without a heart monitor, and I would probably never have used it, if I had not experienced several days of exhaustion after days spent walking in the country while taking a devil-may-care attitude to my heart rate!

Copyright is hereby claimed by the author, but at the same time I give my permission for free use of the material to be published either in part or whole.

Figures 1, 2a, and 2b are below.

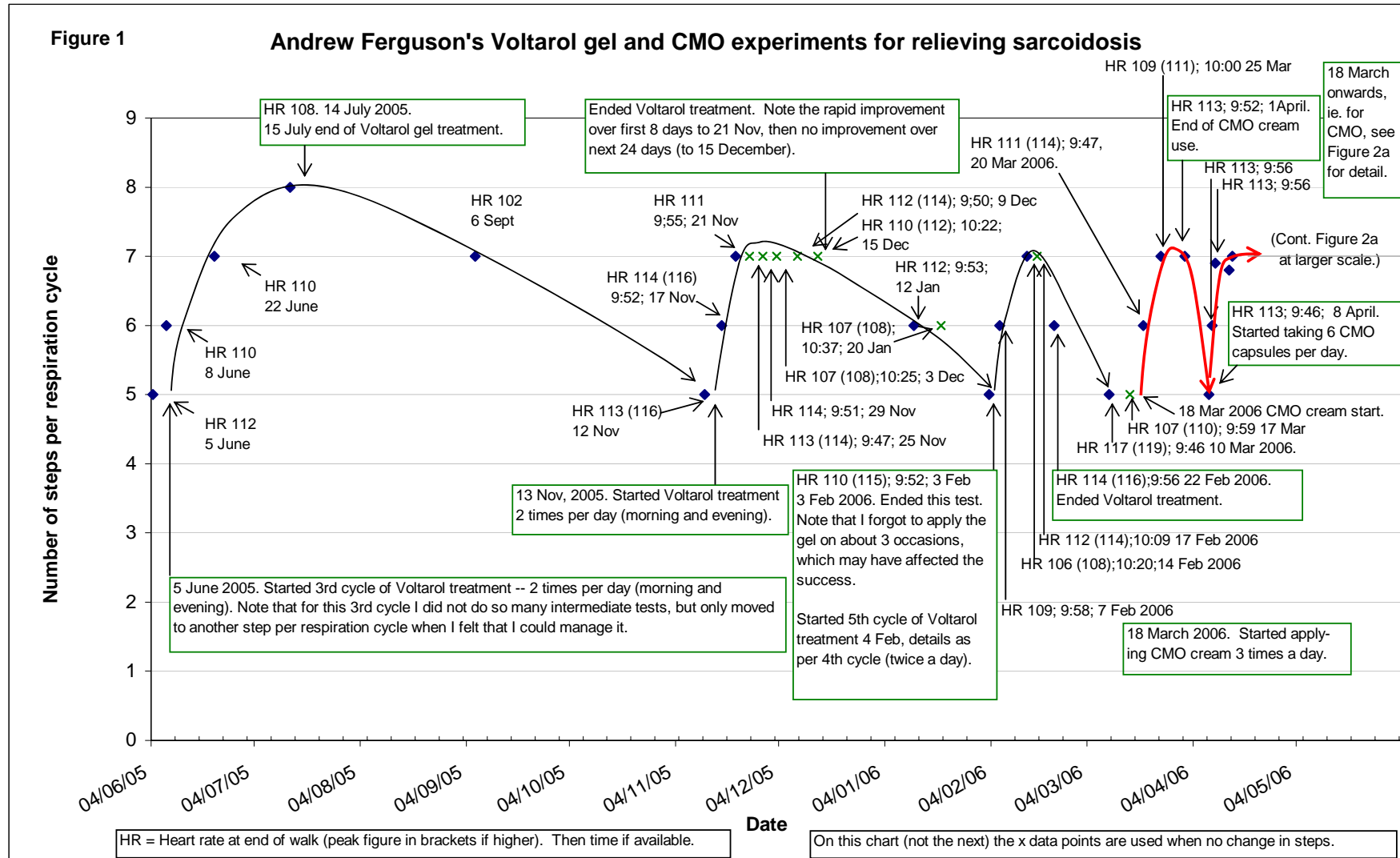


Figure 2a

Andrew Ferguson's CMO experiment for relieving sarcoidosis

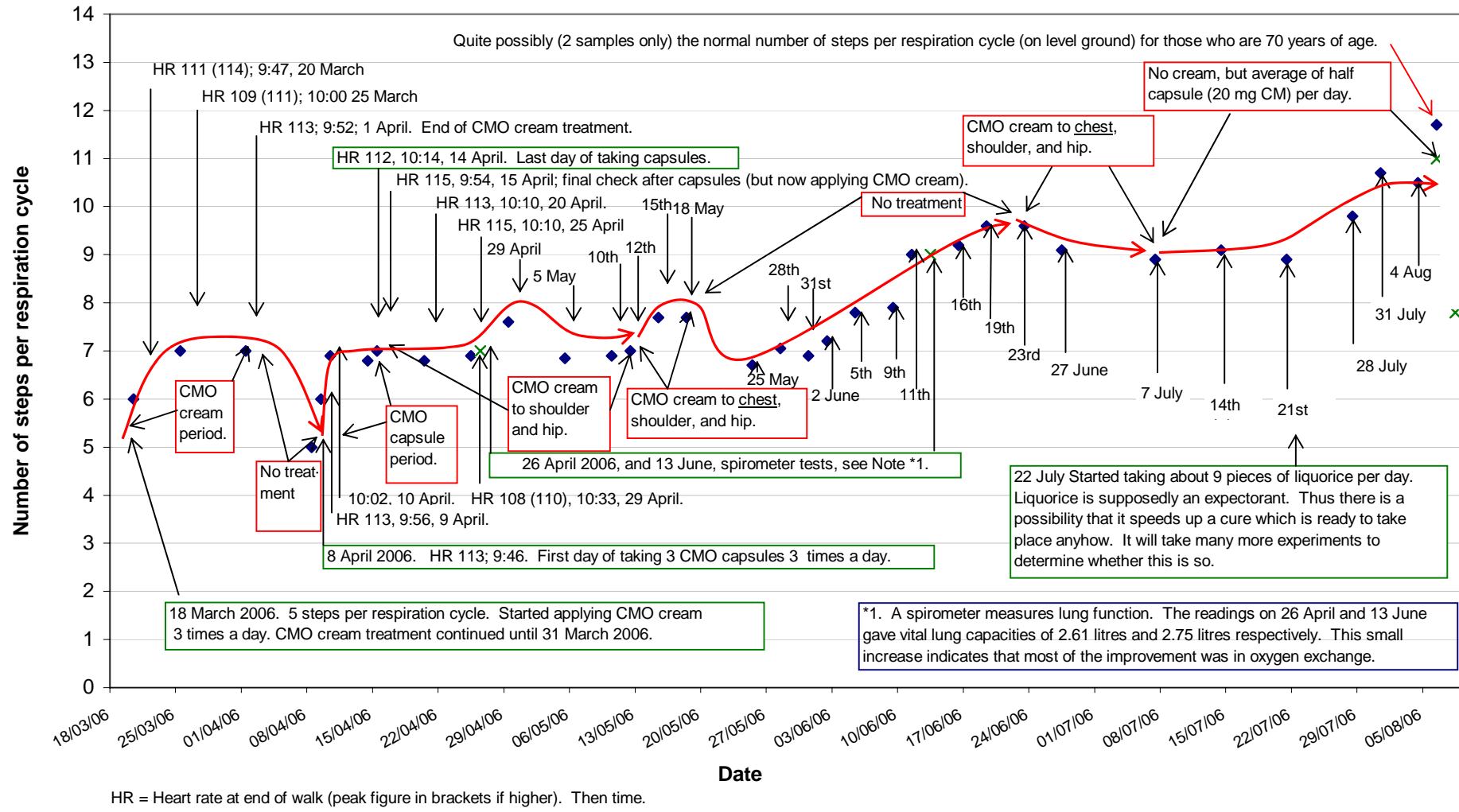


Figure 2b

Andrew Ferguson's CMO experiment for relieving sarcoidosis

