

SILA NEWSLETTER

December 2002

Dear SILA Supporter,

It is very heartening to have feedback from the last SILA newsletter and learn that the information given was useful and the symbol of the snowflake was much admired. It may seem a bit early to look forward to June 2003, but I have been sent details of the **Alexandra Rose Day's Flag Day**. The ARD scheme is simple because ARD produces all the materials needed and handles the official returns to local authorities. This would mean that SILA could promote public awareness and collect from the public by street collections and at supermarkets etc. SILA can display its own name and publicity material. All money would be banked for SILA and a small percentage would be given to ARD for costs. If there were sufficient SILA volunteers in different areas then it could make a difference not only financially but also in getting the message across about sarcoidosis. I hope that any volunteers can contact me if they can take part. More information can be got from ARD 2a Ferry Road, London SW1 3RX also www.alexandraroseday.org.uk Thanks are due once again to those who renew their subscriptions to SILA so promptly and all those who add donations, also the students of Saltash College who organised a Playstation tournament to raise money for SILA. In the next issue of SILA Newsletter, there will be a review of **Me and Sarcoidosis** (Revised Edition) by **Gilbert Barr Jr.**

I wish all SILA supporters a

Very Happy Festive Season

And A Good New Year.



Heather Walker

EDITOR

SILA UP-DATE

May 27, 2002

Desmond Wigglesworth SILA Trustee and Assistant Treasurer attended the opening of Pharmacia's new research centre at High Wycombe by Lord Hunt the Junior Health Minister responsible for pharmaceuticals. During the lunch that followed Desmond met the Director of Research at the new centre and discussed the lack of research into **sarcoidosis** and what could be done. Desmond also met another guest who has subsequently taken 2000 of **SILA's** threefold leaflets for distribution to medical and media personnel. Desmond used his experience as an accountant and also his knowledge of his sister who has been a **sarcoid** patient for over 30 years, to network successfully on behalf of **SILA**.

12th September 2002.

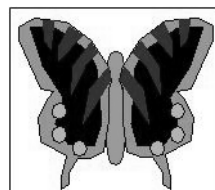
Heather Walker Secretary attended the Southwark Voluntary Section Forum arranged by SAVO (Southwark Action for Voluntary Organisations) which included lunch and networking. **SILA** set up a stall at the Forum held at Cambridge House & Talbot, Camberwell SE5. This was an opportunity for the secretary to distribute literature and answer questions about **SILA** and **sarcoidosis** to a wide variety of people concerned with Area Community Councils and the Voluntary Section. In turn SAVO was able to provide **SILA** with help in its IT sector.

On October 22nd 2002

Heather Walker Secretary attended the launch of Ask About Medicines Week at the House of Commons. AAMW is a new initiative to improve the quality of UK medicine taking. Open dialogue between patients and the health professions was encouraged. The launch was presided over by Dr Howard Stoate MP Chairman, All-Party Pharmacy Group. Dr Stoate is the only MP who is also a practising GP. The Patient View was put by Steve Hawley of the Cancer VOICES Advisory Group. The Secretary has faxed for future information about AAMW.

All correspondence should be sent to

**The Secretary, SILA
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Or e-mail to:
info@sarcoidosis.org.uk**



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A Patient's Story

I was diagnosed with sarcoidosis about two years ago after having had an operation to remove an enlarged lymph node from just above my collar bone; an earlier MRI scan of my neck and chest had detected several such nodes and I know now that at first it was feared that I might have a form of lymphoma. When, thankfully, this proved not to be the case, TB was suspected (and then eliminated) as by then I had developed a dry cough and diffuse shadowing on my lungs, but I was soon to learn that these are also symptoms of sarcoid. The excised lymph node eventually tested sarcoid positive and this, together with a CT scan of my chest and further X-rays and blood tests, confirmed the diagnosis. I was most interested to read the booklet by Rose Bartholomew-Thomas* because it mentioned in the introduction that she had been diagnosed when her daughter was young and that she had intended to postpone having a second child until the condition went. Well, I have a similar story. Although my diagnosis was made only recently, my consultant feels that my condition is chronic and has probably been around, waxing and waning for most of my adult life - I am now 60. For about 30 years I have coped with feelings of almost perpetual lethargy interspersed from time to time with periods of real fatigue, breathlessness and apathy, which have variously been diagnosed as post-natal depression, chronic fatigue syndrome and "all in the mind". My first episode of fatigue occurred after the birth of my son and lasted for several years. Like Rose, I too decided to postpone having a second child until I felt better, but I never really did and so I have only one son. Neither did I ever feel well enough to return to my teaching career, still no diagnosis however. Over the years all blood tests have been normal, no anaemia or hypothyroidism, but once, when complaining of shortness of breath I failed to perform adequately on a lung function test administered by my GP he remarked that I couldn't have been trying, but nonetheless he grudgingly wrote "dyspnoea" on a form and sent me to the local hospital for more blood tests. At no time, however, was I sent for a chest x-ray. One consultant I

was referred to suggested I go home and drink a glass of Guinness every day; another referred me to a psychiatrist. Consequently, in the end I gave up complaining about my tiredness and built a somewhat restricted life around it which meant frequently sleeping in the afternoons (it was wonderful to be able to do this once my son had started school), seldom going out in the evenings and never going on holiday. My poor, long suffering husband has come to accept all this and despite his own diabetic problems (four insulin injections a day since the age of 30) has been a tower of strength throughout. We prop each other up I guess! This time round the severe symptoms did not really set in until about six months after my diagnosis. I now have the usual fatigue and breathlessness but also a dry cough and lots of aches and pains—or could the latter just be due to my age? Who knows? In general I find sarcoidosis is a condition which evokes little sympathy. Apart from the fact that most people have never heard of it, I've also been told "**My daughter had that but it only lasts about six weeks, you should be over it by now.**" Others ask. "**are you sure it's not TB/ME?**" "**Yes I am sure.**" "**They don't seem able to get to the bottom of your problems do they?**" "**Yes they have done.**" "**You look very well so it can't be serious.**" "**Maybe not but its still a very debilitating condition**",.....and so on!

I do hope I haven't bored you with my ramblings; it's just so good to get it all off my chest (no pun intended!). It's a relief to know what's wrong with me at last but I'm just sorry there isn't a quick fix so that I could perhaps spend the autumn of my life brimming with energy and able to do all the things I missed out on in my youth; maybe behave a little outrageously in my old age! Failing that however, "Take one day at a time" seems to be the best philosophy.

NL—Saltash. Cornwall

**So You Have Sarcoidosis! By Rose Bartholomew-Thomas Available from Heather Walker, with a S.A.E usual address, as overleaf.*

Articles Wanted

What sort of articles would you like to see in your Newsletter? Any suggestions would be of interest to the Editor, why not write and let her know your views. Would you like a FYI section, or perhaps a FAQ section?

Do you want to send in more personal stories like the one above? Please send in your stories for consideration and publication to SILA at the usual address given on the previous page.

The SILA website is in the process of being updated, and improved, any suggestions would be welcomed.

Remember that SILA can supply a **video on sarcoidosis** which is available for a returnable deposit of £20, contact SILA at the usual address.

SILA welcomes feedback on the Newsletter.
Annual Subscription to SILA is £12.

THANK YOU.

SILA NEWS - REGISTERED CHARITY NUMBER 1063986