

S.I.L.A NEWSLETTER

SPRING - 2004

Dear SILA Supporter,
2004 continues with more requests for help and information from sarcoidosis patients and I do not doubt that will be the pattern throughout the rest of the year.
I am pleased that the request for starting a branch of SILA has resulted in one SILA member, Shelagh Masters, from Yorkshire, contacting her local newspapers, and she has already had useful responses, and an interview with one newspaper. Watch this space, for more of these promising developments.

Another SILA member has written to me with news that she has lived with sarcoidosis for three years and managed to avoid taking medication and felt that swimming did her a world of good. When she could not maintain a regular exercise regime of swimming three times a week, then she could really feel the loss of benefit. Not everyone can manage to do this, and any course of treatment, should be discussed with a doctor and medication not stopped first without doing so, it is worth considering how much self-help and sarcoidosis go together. This patient also recommends holidays abroad near the sea which helps tremendously. Not everyone is able to do take a holiday of this type or even get away from home at all. I have been sent a brochure: 'Holidays for Special People' which is suitable for single parents or low income families. These holidays are in the UK. For more information telephone The Scout Association Information Centre 020 8433 7100.

All the Best for the Rest of 2004



Heather Walker

EDITOR

Spring SILA update

Heather Walker's article 'TB or not TB?' about sarcoidosis was re-printed in CONNECTIONS magazine. (Autumn 2003 edition)

Gilbert Barr Jr. author of *Me & Sarcoidosis A lifetime Partnership*, which was reviewed in the March 2003 SILA newsletter is working on a new book which is going to cover sarcoid patient's stories, including international stories. Gilbert Barr's address is:
17634 Melrose Street, Southfield. MI 48075 USA. (telephone number (248) 552 0443) for anyone who would like to contribute their story for consideration. Heather Walker (whom Gilbert first contacted) has contributed her sarcoidosis story. Gilbert Barr's email address is gilbert@gilbertbarrjr.com

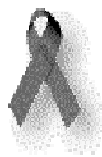
BLF (British Lung Foundation) is looking for case studies people willing to talk to the press. The person to ring is Laura Leonard on 020-7688-5564 or email laura.leonard@blf-uk.org

12th October 2003 Kim Yorke completed an 8 mile sponsored run in the Kingston Running Festival and raised £400 for SILA. Many thanks and congratulations to Kim. Kim's friend has been a sarcoid patient for nearly a year but she is finally on the mend. She no longer needs her wheelchair anymore. She is driving a car and has got a part-time job. Kim, now working in Australia hopes the money she has raised will help towards finding a cure for sarcoidosis

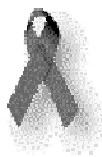
26th January, 2004. SILA Trustee, Daisy Anderson attended a meeting of the Southwark Trustee Network, held at SCCF, 32-36 Rye Lane, London SE15. (6.30pm to 8 pm.) A charity trustee network shares a common interest in pooling information and providing mutual support.

Fundraising Opportunities
www.ukoutdoorpursuits.co.uk

S.I.L.A. has a video about sarcoidosis, that you can view, for a deposit of £20. which is refundable.



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A Patient's Story

'I have recently been diagnosed with sarcoid, and looking back I now realise that most of my health problems have probably been due to this disease. I have been having problems with my eyes for about two years, and I am now presently waiting confirmation from the Ophthalmology Department, for an operation to unblock one of my lacrimal ducts. I had a partial thyroidectomy in September 03. As well as removing part of my thyroid my consultant also did a biopsy of my adenoid tissue. This resulted in the diagnosis of sarcoidosis. I had previously had an ultra-sound and needle biopsy of my thyroid and lymph glands in my neck. It was constant enlarged lymph glands which made me visit my GP in the first place. I have also been seen by a doctor at the Chest Clinic in October 03 and my next appointment was in the new year. I was told that I will have tests done on my chest and lungs and have an x-ray. I will also be seen by my consultant for the follow-up of my thyroid/blood tests, and to check on my nasal polyps. The only medication I am on at present is a nasal spray. My main concern at the moment is my eyes, especially the right one which is always red and sore. I was admitted to hospital in November with orbital cellulites. I have found lately that I have been very tired and have suffered from aches and pains. My eyes have always been very sensitive to light. I do not have any problems with skin rashes and breathing. Although my nose is always blocked which I presume is due to the polyps. It is just one long round of hospital visits and tests. (SC)

SILA has a leaflet on Sarcoidosis and Eyes, available on receipt of SAE to address below.

Note: Would you like to tell 'your story' send it to Heather Walker at the usual address.

New Scheme for giving to charity through tax return From April 2004 people who complete a Self Assessment tax return will be able to nominate a charity to receive all or part repayment due to them. The Inland Revenue repaid around £3 billion to nearly 3 million Self Assessment taxpayers last year. The new scheme will have real advantages for participating charities. The form will incorporate a Gift Aid declaration. Gift Aid Tax will be paid without the charity having to make a claim. For the first time charities will benefit from Gift Aid on anonymous donations. A list will be published of participating charities, from which donors will choose. The list showing the charity name and address together with an identification code will be available on the Inland Revenue website. Donors will enter the code for their chosen charity on their tax return.

Useful Websites.
www.sarcinfo.co
<http://update-software.com/national>.
 (National NHS research projects database)

Please Note if your address details are incorrect, kindly notify us, so we can amend our database. Thank You

All correspondence should be sent to:-
 The Secretary, S.I.L.A.
 Chest Clinic Office
 2nd Floor Admin Block
 King's College Hospital
 Denmark Hill
 London SE5 9RS

Or email to info@sarcoidosis.org.uk

The new Pharmacy Contract - Tapping Community Pharmacy's Potential.
 The new contract is due to be negotiated by April 2004.

Proposed services may include Diabetes Screening, Coronary Heart Disease Screening, Healthy Living service. Palliative care services. Out of Hours Service. Smoking cessation service etc., For more information.

www.psn.org.uk
 Pharmaceutical Services Negotiating Committee.
 Direct line 01296-438426

SILA subscription is still £12 p.a
 Donations to SILA always welcomed.