

# S.I.L.A NEWSLETTER

## FIFTH ANNIVERSARY

1997 SARCOIDOSIS AND INTERSTITIAL LUNG ASSOCIATION 2002

Dear SILA Supporter

I am sorry that yet again there has been a delay between this edition of the SILA newsletter and the last. This was mainly due to the computer and printer which produced the last few issues not being SILA's own property. Now that a new computer and printer have been purchased from the SILA funds it is hoped that the newsletter can be produced on a regular basis.

This year marks an important landmark for SILA as it will be five years in August since SILA became a registered charity. Previous to 1997 the Sarcoidosis Association UK was the registered charity for sarcoid patients. Now that the Sarcoidosis Association UK has ceased, even more work will fall on SILA. It is therefore more vital than ever that SILA can continue to rely on regular donations and subscriptions if it is to meet the challenge of the next five years and beyond.

The ALEXANDRA ROSE DAY raffle was a first for SILA and thanks are due to all those who bought and sold tickets and helped to raise £150. for SILA.

SILA is grateful, for the many donations made in 2001/2002 including those made by the family, friends and work colleagues of the late Sonia Taylor, whose employers Ernst & Young Donated £500. to SILA

SILA is pleased to welcome all new members and all who have continued to renew their subscriptions so promptly.

Don't forget that a video on sarcoidosis is available from SILA in receipt of £20.00 Returnable deposit

Also don't forget that SILA support meetings held on the first Thursday of the month (except in August) at King's College Hospital, Denmark Hill, London SE5 9RS in the Belgrave Room (opposite the Boardroom) on the ground floor from 7.00pm to 9.00. All are welcome, including family and carers.

**HEATHER WALKER**  
Editor

## SILA UP DATE

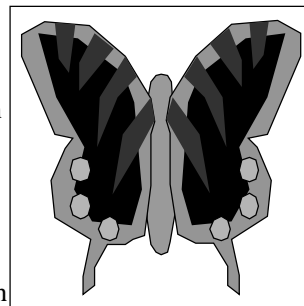
Meeting held at King's College Hospital Boardroom on **15th May, 2001** attended by SILA members and supporters.

The main business of the meeting was to discuss responsibility for drawing up Literature and Information Sheets.

**27th August 2001.** SILA's address appeared in WOMAN magazine Again resulting in more letters asking for help and information about sarcoidosis.

**20th September 2001** SILA's Annual General Meeting was held at 1 Myron Place, Lewisham SE13 at 7.00pm. The following officers were appointed to the **Executive Committee:-**

Secretary	Heather Walker
Chair	Paul Sinclare
Treasurer	Paul Sinclare
Co-ordinator	Colin Wintersgill
Minutes Secretary	Heather Walker
Vice Chair	Theresa Gray
Assistant Treasurer	Desmond Wigglesworth
<b>Trustees:</b>	D. Anderson
	T. Gray
	H. Walker
	D. Wigglesworth



The proposed meetings of EPOS of which SILA is a member, had to be **cancelled in 2001**. But SILA helped with a page for use by EPOS

(European Association of Patients' Organisations of Sarcoidosis and other Granulomatous Disorders) that has since been put on their web-site.

**18th February 2002,** SILA Secretary, Heather Walker, attended the Patients' Forum Annual Conference 2002, held at Friends House, Euston London. SILA is a member of the Patients' Forum. The focus of the conference was: "Involvement in the NHS: Meeting the challenge of hard to reach groups." Keynote speaker Nigel Crisp, Chief Executive, Department of Health and the NHS.

**24th February 2002,** A Charity Event was held in aid of Sarcoid, organised by Lady Carolle, a sarcoid patient. The event was held at the Café de Paris in aid of the UCL Hospital Charity Aid Foundation. SILA members and supporters attended this event, with a Host of Stars, which helped to raise over £4000. for sarcoid research

**18th March 2002.** SILA Secretary, Heather Walker attended the Pharmacia Lecture at the Royal Society, Carlton House Terrace, London. Given by Dr David Kessler entitled "A Great Public Health Battle," Dame Helena Shovelton the new Chief Executive of the British Lung Foundation attended the Pharmacia Lecture. Dame Helena outlines what she wants to do and how she lived with sarcoidosis in the Breathe Easy Magazine No 43, Winter issue which also contains an article on sarcoidosis by Dr Helen Booth, Consultant Physician at UCLH.

\*\*please see note over page regarding copies of articles

## SILA UP DATE CONTINUED

22nd April 2002,

Dr Miriam Stoppard's page in the DAILY MIRROR answered a letter about sarcoidosis and published SILA's address which resulted in more letters and e-mails asking for help and information about sarcoidosis.

\*\*Please note. Copies of both articles from the Breathe Easy Magazine are available to you, but please send a SAE, and state which article you would like.

### Announcement

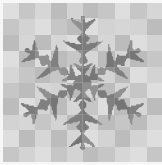
As no two snowflakes are identical and no two individuals with Sarcoidosis appear to have identical symptoms. Therefore, the

### *SNOWFLAKE*

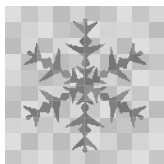
has been chosen to symbolize

**Sarcoidosis Throughout**

**the World.**



All correspondence please to  
The Secretary, SILA  
Chest Clinic Office 2nd Floor Admin Block  
King's College Hospital  
Lodon. SE5 9RS  
e-mail info@sarcoidosis.uk  
www.sarcoidosis.org.uk



### **Return Address**

Secretary, SILA Chest Clinic Office  
2nd Floor Admin Block  
King's College Hospital  
Denmark Hill  
London SE5 9RS

## HELP ADDRESSES

### **NHS Direct**

Confidential Healthcare 24 hours a day  
telephone 0845 4647  
www.nhsdirect.nhs.uk

### **Helpfinder**

A British Red Cross Northern Region Confidential information service.  
Freephone Number. 0800-169-2030  
Monday to Friday 8.00am-8.00pm

### **Disability Information Resources**

Monday to Friday 10.00am to 1.00pm and 2.00pm to 4.00pm  
Telephone Number. 01306-87516  
e-mail is : info@diss.org.uk  
Internet www.diss.org.uk

### **For Oxygen on Holiday**

Help available for UK and selected European destinations  
from Air Products  
Freephone No. 0800-373580  
e-mail is : holiox@apci.com

### **National Osteoporosis Society**

Camerton  
Bath BA2 0PJ  
Helpline, telephone 01761-472732  
Website www.nos.org.uk  
E-mail info@nos.org.uk  
Leaflet Available. Corticosteroids & Bone From NOS

### **The Steroid Aid Group**

PO Box 220  
London E17 3JR  
Please enclose a SAE - A5 size

**SILA NEWS**

**REGISTERED CHARITY NUMBER**

**1063986**