

All correspondence and leaflets requests, should be addressed (please enclose a SAE for a reply with four 1st class stamps) to:

The Secretary. SILA
c/o the Chest Clinic Office
2nd Floor Admin Block
King's College Hospital
Denmark Hill
London. SE5 9RS

Support Meetings

are held at this venue on the first Thursday of each month with the exception of August when there is no meeting.

7.00pm - 9.00pm in the Belgrave Room.

All are welcome,

A video on the subject of sarcoidosis is available by sending a refundable deposit of £20 to the above address.

Annual Subscriptions
to SILA is £12 per annum

SILA welcomes comments and contributions to the SILA newsletter. Also fundraising ideas or initiatives.

SILA's Charity Registration No. is 1063986
email address. info@sarcoidosis.org.uk

Dear SILA Supporter

I have just realised that this newsletter is a 10th Anniversary Issue. The first record of names who were receiving the newsletter I have in my post-book is February 1995. I am pleased to say that some of the names on the 1995 list are still on the list, so they have kept in touch with what SILA has been doing for 10 years. Now the list of recipients of the newsletter has grown considerably over the years. Now Henry Shelford (who featured in the Autumn 2004 SILA newsletter) has taken over the revising of the SILA's web-site, at his own expense, SILA newsletters will be put on the web-site, thus reaching a much larger readership. Certainly it will be much wider than the readership in 1995.

I was asked this year to supply information about sarcoidosis for an article in THE TIMES published on 14th June entitled TOO YOUNG FOR SUCH A BURDEN? by Kathleen North. A SILA member sent me a copy which I had not seen. The article deals with an aspect of caring for sarcoidosis patients (and other illnesses) by children under the age of 18 which I had not fully realised existed so widely. If any SILA member whose family is in this position, want more information on activities and support, they can see www.childrenssociety.org.uk. A book is also recommended: Coping with Life's Traumas by Gladena McMahon (Gill and Macmillan, £8.99)



I do hope that everyone
has a
HAPPY NEW YEAR.

Heather Walker

A Patient's Story

A Patient's Story

I had a very bad fall in the street in December 1999, in which I smashed up my face very badly, breaking my front teeth and a couple of ribs. It took me a long time and many visits to the dentist to recover. In fact I still felt very shaken in March 2000 and I started to get chest pains and shortness of breath. I went to my GP who said he thought I may have the symptoms of angina and gave me a spray to try. He said that if I had relief then it would prove that I had angina. Well, it made no difference and in the June I began to get more breathless. I found walking up the stairs and any small incline very difficult. I began to feel very old (I was only 60 years of age!). In July I began to notice some lumps appearing around my thumbs. The lumps then started to go up my arms so I went to see my GP. He was mystified but said we should keep an eye on them. A couple of weeks later I became to gasp for breath and the lumps began to look like long pieces of knotted string and I had more, down my legs, in my chest and under my arms. I had to ring the doctors for an emergency appointment and I had to see a locum as my usual GP was unavailable. The locum was very concerned and called in a colleague and they called the local hospital immediately and said they were sending me down as a matter of urgency. When I arrived at the hospital I was put in a wheelchair and told to stay very still and quiet. The suspected that I had a clot on the lung so I was treated with great urgency. I had numerous tests and X-rays which confirmed that I did not have a clot on the lung. The doctors then turned their attention to the lumps which they said were enlarged lymph nodes. They removed on from my arm for a biopsy I was very concerned by then as I thought that I might have cancer but it was confirmed that I had Sarcoidosis. I was told that I should have steroids as this was the only known treatment. As I did not know very much about Sarcoidosis and the specialist did not know very much I was given an appointment to visit the lung department in a couple of weeks. While I waited for these two weeks I did some research on the internet and contacted someone at King's College who was very informative. I

SILA WEST MIDLANDS BRANCH.

The first meeting to f the SILA West Midlands Branch was organised by a SILA member Carol Bashford at Laurel Court, 25 Oxford Road, Moseley on Monday 29th November. The meeting was well attended and everyone had a chance to speak about their experiences of sarcoidosis and plans for the future were outlined by Simon Ellis. Everyone present welcomed the opportunity to meet up in this way and group photographs of the event were taken. The next SILA West Midlands Branch will be held on Monday 28th February, 2005 between 7 - 9 pm at Laurel Court 25 Oxford Road, Moseley B13 9EH A-Z reference page 90B. More information about the above meeting can be obtained from Mrs Carol Bashford, 38 Yew Court Avenue, Harborne, Birmingham B17 9TR. 01210427-5462 or email carol_bashford@hotmail.com.

INFORMATION RECEIVED.

The British Lung Foundation Help line.

The BLF Help line will be launched on 4th January 2005 which aims to provide vital information and advice to anyone concerned about any lung disease.

More information from British Lung Foundation 73-75 Goswell Road, London EC1V 7ER. Tel:020-7688-5555

Email enquiries@blf-uk-org.
website www.lunguk.org.

NERIL (The North East Essex Resource Centre and Information Line) a project of Malden (Essex) Mind, is a telephone help line for anyone over 16 (or their carer or relative) resident anywhere in North Essex (Epping, Harlow, Uttlesford, Chelmsford, Maldon, Braintree District, Colchester and Tendring) who is experiencing mental health distress.

0845-0900-909 4pm to 8.00 am 7 days per week.

SILA Up-Date

SILA Secretary, Heather Walker attended the Voluntary Sector Forum Meeting on Thursday, 30th September at Cambridge House, Camberwell. London SE5. The meeting was organised by SAVO (Southwark Action for Voluntary Organisations) and was attended by over 60 people. The emphasis was on the need for dialogue with politicians and was addressed by two Group leaders of the Council. Three workshops followed dealing with: How can the Council and the community sector ensure that the community councils can be more reliable? How can the needs of new community groups be met? To what extent can the Council and SAVO, capacity build small local agencies?

SILA NORTH-EAST for the time being can no longer be run from Newcastle. For that reason funds totalling £3425 have been transferred from SILA North-East's Bank Account to SILA's Bank Account. SILA is very grateful for all the work and effort put in by Irene Allen (Secretary) and her family to raise this sum and spread the word about SILA. It is planned that funds will be continued to be raised for SILA from the North-East and then sent on to SILA.

Thanks are due to the anonymous donor of £5 to SILA who took part in the FLORA LIGHT CHALLENGE FOR WOMEN 2004. 27000 WOMEN TOOK PART IN THIS EVENT HELD AT London's Hyde Park and also in Birmingham on the 5th September 2004. £5 of the £12 entry fee was donated to a charity of the runners choice.

Anyone interested in partaking in the FLORA LIGHT CHALLENGE FOR WOMEN 2005 should write to The London Marathon Ltd., PO Box 1998, London SE1 OWY or telephone 020 -7902-0200

understood that Sarcoidosis was a strange disease, nobody new how you got it and that it could go away as quickly as it had appeared or it could come and go or stay with you for life.

The specialist I saw in the lung department sent me for a chest X-ray and lung function tests. He seemed very knowledgeable on the subject although he said that he did not see many cases on our area. He said he would advise steroids but it was up to me whether I wanted to take them as they do have some unpleasant side effects I decided I would do without them he said he would see me every 4 months and I would have regular chest X-rays and lung function tests. I was advised to rest as much as possible and only do things which I felt able to do at the time, but also to do a little walking each day although I was very breathless. I took his advice but found that the mornings were my best time when I could have little walk, do a little housework etc. by lunchtime I felt as though I had literally run out of steam (as though my batteries had run down, so to speak), so I would then take it easy.

A friend of mine handed me a cutting from a magazine one day and said 'is this what you have -sarcoidosis- because it is mentions in this article. It was an article praising the beneficial effects that Devil's Claw had on arthritis sufferers and at the end it said that it could also be beneficial to people suffering with sarcoidosis. So where do you think I went the next day , to the local health food shop of course.

I have been taking these tablets since that day and although I still have some problems I feel a lot better and the specialist has been surprised by my progress and has written 'takes Devil's Claw' in my notes. I still visit the hospital regularly for my tests and see the specialist and he says they will continue as he says it could return with a vengeance at any time. I do now have an irregular heartbeat for which I take aspirin daily.

A Patient's Story

And pains in parts of my body and a nasty back pain which is under investigation. I have more energy than I did but there are still some days when I run out of steam but I am nowhere near as bad as I was. Whether the Devil's Claw has helped or whether it is psychological I don't know but who cares! Incidentally I have been having the odd dizzy spell which lasts for split seconds. The world around me turns upside down and then rights itself. The specialist thought it might be the irregular heartbeat but I was talking to a pharmacist about it and he said that it sounded as though there was something that was putting the balance of my brain out for a few seconds, he sort of thing which happened to people who are travel sick because the brain gets disorientated. He said that in this instance it was because small pieces of calcium break off and get into the brain and puts the balance out. It got me and him thinking because people who suffer from sarcoidosis make an excess of calcium and we wondered if this is why I have the dizzy spells and whether they could be prevented by taking travel sickness pills -- the sort which work by balancing out the brain not the ones which only sort out the nausea in the stomach. I will ask my specialist next time but if any members have had this experience I would be interest to know.
AD. Suffolk.

A Patient's Story - Update.

In December 2003 newsletter under a Patient's Story heading, an account was given of E Gray's son, Harry and his progress with the treatment of his neurosarcoidosis, this account followed on the account Glyn J's A Patient's Story in the Summer 2003 newsletter, who was told that neurosarcoidosis

appeared to be very rare. E Gray From N. Ireland wrote again when sending in his annual subscription:

"We had great news with the final result of Harry's MRI scan on 15/11/04, the steroids treatment has completely cleared his brain of sarcoidosis, his neurologist is now slowly taking him off Tegretol 100mg per month and stopping his steroid. This could all take some time, because as he comes off the drugs he still has small seizures, but his consultant says that this will happen as the Tegretol in the first place was to prevent fits. But the change in Harry is dramatic, he is now very confident and eager to resume a normal life and get back into society. I hope this give some of your members , hope."

INFORMATION RECEIVED.

Stress and Depression Confidential Helpline.
Telephone -01622-717-656 (normal rates)
Callers can ask the helpline to ring back.
9am - 9pm 7 Days per week.
Also runs a free internet course on
Stress Management.
stresscourse.tripod.com (it is important not to self-diagnose as suffering from stress, but consult your doctor first of all.)

Request Help from Members

More patients' stories are needed for the newsletter and the new web-site. Get writing now, please. Thank you. From Heather.

