

S.I.L.A NEWSLETTER

SUMMER 2003

Dear SILA Supporter

It will be seen from further reading of the newsletter that recent requests for people willing to help run branches of SILA are beginning to show results. Denise Lewis and her husband Paul, are interested in trying to start a branch of SILA in North Yorkshire. If anyone wants to lend support and or find out more the address is : 22 Sandybed Crescent, Scarborough North Yorkshire Y0125LS pauldenise@lewis2163.fsnet.co.uk.

Also in the North East John Burdis, 20 Rochdale Street, Wallsend, Tyne & Wear NE28 8LA and his mother-in-law, Mrs Irene Allan, 81 Whinneyfield Road, Walkergate, Newcastle NE6 4RQ are in the midst of planning to set up a branch of SILA in the North East and also anyone who wants more information and or to get involved can get in touch. Irene is the mother of Toni Farr who features later in the newsletter. I hope that these new ventures will perhaps inspire others to start up more branches so that much more help can be given and more meetings of sarcoid patients, their relatives and friends can take place.

AMOUNTS OF MONEY RAISED FOR SILA SINCE PUBLICATION OF THE LAST SILA NEWSLETTER IN MARCH 2003

Marathon £909.50

Charity Night held on the Fullerton Park, Glasgow. Organisers Jacqueline Highfield and Neil Riddell. Total of £1637.07

SILA Northeast £2997.00

Thanks are due to all those who contributed money, time and effort to raising these grand amounts.

There will be an AGM for SILA on September 4th 2003. See overleaf for details, if you do not receive an agenda, and you would like to attend, contact Heather Walker direct via email WalHt@aol.com

We at SILA wish you all a very happy and healthy summer.



Heather Walker

EDITOR

SILA UP-DATE.

Sunday 13th April, Pauline Virgo ran again for SILA in the Flora London Marathon and finished in 3hours 54mins.

Thursday May 1st 2003, Pauline Virgo attended the SIL A Support meeting to hand over the first instalment of the sponsorship money collected for her participation in the Marathon. Also at the meeting was Nicky Saynor, Public Involvement Facilitator Southwark Primary Care Trust Dulwich Hospital, East Dulwich SE22. The PCT is a new NHS Trust which has responsibility for making sure there is provision of healthcare across the borough. Ms Saynor explained to the support group about the PCT and listened to members' views on health services and priorities. In exchange Ms Saynor was made aware of the problems of sarcoid patients and how much is needed to make others aware of all the problems involved, when seeking treatment.

Saturday May 10th 2003 Heather Walker Secretary SILA received a Civic Award from the London Borough of Southwark for voluntary work for SILA. The award was made at St George's Cathedral, Southwark, and there was after the ceremony, for all the recipients of civic awards and guests, a buffet lunch under a marquee outside the cathedral.

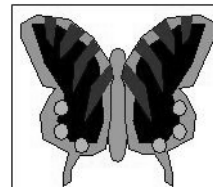
Sunday May 11th 2003 Heather Walker was in the audience of the Jonathan Dibley programme, on the suggestion of the Patients' Forum of which SILA is a member. The guest on the programme was John Reid (now Health Minister) and the discussion was on such subjects as Foundation Hospitals, NHS. The programme was recorded live and took place at London Weekend. SE1.

Saturday 25th and Sunday May 26th 2003 European Association of Patients' Organisations of Sarcoidosis and other Granulomatous Disorders (EPOS) General Assembly took place in Dusseldorf. Although SILA was not able to send a delegate this year, full details of the proceedings have been sent to the Secretary and SILA where possible has a say in what is proposed. Also a selection of articles in English from medical journals relating to sarcoidosis (sleep problems, stress etc.) has been sent from the German members of EPOS for which SILA is very grateful.

Monday 9th June 2003 John Burdis and Toni Farr ran in the Blaydon Races* to gain sponsorship with tee-shirts with Sarcoidosis Awareness and have opened a bank account in SILA's name to bank the sponsorship pledge money. The race was also in memory of Robert Farr who died aged 33 years in January 2002. Toni is his widow, and John and Toni completed the distance of 5.7 miles in 55 minutes. It is hoped that as a result of this effort a branch of SILA in the North-East will be opened soon.

Thursday July 3rd 2003 Heather Walker, Secretary went to a Reception held by Ken Livingstone, Mayor of London, at City Hall for recipients of Civic Awards.

*see photos overleaf



A Patient's Story.

My husband ~Glyn's history of illness started back in 1988. He had two lots of illness with each time meningitis being suspected. This carried on till the end of August of that year when a friend got him into another hospital and they found he had encephalitis. * After three weeks' rest he came home and after a short time off work he returned to work. Over the next 14 years Glyn has had headaches and when they become bad ones we always put them down to his sinus. Along with the headaches Glyn had aching bones, being very tired, dizzy spells, bloodshot eyes and face paralysis. We have blamed gloss paint, varnish, dust and then we found he had polyps. The first time they were taken out he seemed to improve but back came all the symptoms. The second time he went to have the polyps removed we really thought it would go away. No bad headaches for about 4 months, then a very bad one with the doctor treating him for sinusitis. After twice more taking him back to the doctors I said that he was acting like he did in 1988 being confused and sleepy, so he got him admitted to hospital for a neurologist to see him quickly. They did a MRI scan and encouraged Glyn to go forward with a brain biopsy. By this time Glyn was more like his old self, after being very agitated and talking to no one. He did after 5 days act in a way for the doctors to believe he was a threat to other patients so they put him to sleep for two and a half days. This did him a lot of good like the last time rest seemed to be the cure. We came home and waited for the result of the biopsy which took from the middle of October to 6th December when we were told he had sarcoidosis and he was going to be treated with steroids. We must admit to not asking a lot of questions even to not asking how long he would have to be on steroids. The family doctor said he had been put on Ranitidine and Didronel so would be on them for a while. We go back to the hospital on 7th January and we now have a list of questions to ask. Also that the doctors at the first hospital may not have seen a sarcoidosis of the brain before as it does seem to be very rare. This does mean that Glyn has not seen a sarcoidosis specialist. It would help Glyn a lot to know more about what he has got and what the future holds for him. Once again thank you for giving us that first step so there is someone out there to help him. Is there a specialist Glen can see?

G&AJ.

*inflammation of the brain.



There will be an AGM for SILA (to be combined with the support meeting) on 4th September 2003, at King's College Hospital in London, SE5. All paid up members are eligible to vote. You may obtain an agenda from Heather Walker if you are interested, persons who live near or by will be receiving an agenda with this Newsletter, but all are welcome. Hope to see you there!

All correspondence to
The Secretary SILA
Chest Clinic Office
2nd Floor Admin Block
King's College Hospital
London SE5 9RS

Photo taken by Elaine Burdis 9 June 2003