

SILA

Sarcoidosis and Interstitial Lung Association

GIFT AID FORM

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Surname.....

Address.....

..... Town

County Post Code.....

Optional Details:

Tel.No.....Email.....

*Make your gift worth even more with a Gift Aid Declaration:
If you are a UK taxpayer you can "gift-aid" your donation which means we can reclaim income and/or capital gains tax from the Inland Revenue, thereby increasing your donation to us by 25% at no extra cost to you.*

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Signature..... Date.....

Please ensure that you have completed your contact details above so we can reclaim the tax on your donation.

*To benefit from Gift Aid you must pay income tax to an amount at least equal to the amount SILA reclaims on your donations - currently 25p for every £1 you give, prior to April 2008, 28p. A 3p supplement is paid on donations received between 6 April 2008 and 5 April 2011.

We can either:

- (i) provide you with this form and a stamped addressed envelope to return to the below address
- (ii) email you this form and you can return it by post
- (iii) email you this form, you then complete it, scan it and email back to: info@silas.org

Sila

NOTICEBOARD

Sila

Summer/Autumn 2010

European Medicines Agency Launches New Website

www.ema.europa.eu

Quick Medicine searches. Online Library for those interested in the regulation and safety of medicines.
or
Telephone 0207-523-7795

Talks

Talk on Sarcoidosis to Barbados Overseas Nurses Association on September 4th 2010

Given by SILA Secretary, Heather Walker at Tooting Broadway Methodist Church SW17 7 - 9 pm
Donation presented to SILA from BONA

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Living with Sarcoidosis

SILA member Dr. Joe Gray with his wife gives his personal story at Seminar on Sarcoidosis to UCB employees Bath Road Slough
October 6th 2010

Media

Daily Telegraph 30th June 2010

Mystery Illness Poleaxed Me and Perplexed My Doctors Richard Preston

online version

<http://www.telegraph.co.uk/healthy/men.shealth/7843500/Sarcoidosis-Mystery-illness-poleaxed-me-and-perplexed-my-doctors-html>

or

Daily Telegraph 0800-316 - 6977

Daily Mail September 7th 2010 Ask the Doctor Sarcoidosis

The Times

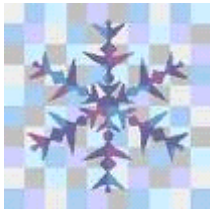
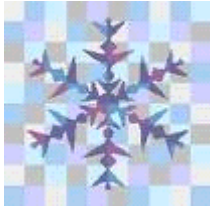
SILA was signature to letter in The Times 26th March 2010
Treat Patients and Carers as Grown-Ups from Jeremy Taylor, Chief Executive, National Voices
For a Full List of Signatures timesonline.co.uk

Donations

Wessex Lacemakers Many thanks to this organisation for their donation to SILA in April.

Sponsorship Forms

SILA can supply Sponsorship Forms for members and others participating in events.



Mailing Address:

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Denmark Hill,
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Registered Charity no:1063986

S.I.L.A. NEWSLETTER 27 SUMMER/AUTUMN 2010

Dear SILA Supporter,

I must apologise for the late arrival of the newsletter, which is due to a variety of reasons, mainly the lack of Patients' Stories and other contributions.

I have chosen instead, to focus on the efforts made by patients to raise money for SILA I have started with the account sent in by member Jane Carter who walked from Bath to London, last year and who illustrated her journey.. I hope that everyone reading Jane's journey will be as full of admiration as I am for all she accomplished

Jane was not alone in raising money for SILA, there was mention in the last newsletter of Scott Hillier running in the Slough Half-Marathon and he was joined by Nancy Cawkwell. Peter

Cross completed the Three Peaks Yorkshire Walk. Emma Shinn and family completed a Sponsored Cycle in August. Bernadette Lenihan from Warwick managed to complete her Sponsored Walk despite the agony involved.!

October 2010 is going to be a busy month for SILA Supporters on the move. Laura Devonish is entering the Cardiff Lloyds TSB Half-Marathon on October 17th. A friend of a SILA member is competing in the Amsterdam Marathon to raise money for SILA. I am sure that everyone will wish them the best of luck in their efforts to reach the finishing line. I hope to report the results in the next newsletter.

In August 2011 Paul Oak is cycling from Land's End to John O'Groats to raise money for SILA as part of Open Challenge, Discover Adventure,

All the participants, (some are sarcoid patients themselves) in these running/cycling/walking events do so either because a friend or family member has sarcoid or in memory of someone they knew and loved, who had sarcoid. They are following in a long tradition of raising money in all sorts of different ways, for SILA. The SILA Newsletter of February 1995 refers to a Garden Brunch and Jumble Sale held to raise money for SILA. In 2003 Pauline Virgo ran the full distance in the London Marathon on behalf of SILA. John Burdis ran the full distance of the Blydon Road Race on 9th June, 2003 on behalf of SILA

If anyone wants to donate to SILA online this can be done on the Charity Choice online Donation Service: www.charitychoice.co.uk

I have been informed that the Sarcoidosis Awareness Society (SAS) created in February 2009, whose progress report by Martine Caitlin and Charlotte Doggett featured in the last SILA Newsletter, has now closed down.

I was sorry to hear of the death of long-term SILA member Ellie Parker on September 14th. Ellie who with her late husband, John, undertook so much work from the start, for SILA, until Ellie was too ill to continue. Without the support and friendship of Ellie and John, SILA would not have made the progress over the years that it has already achieved. Ellie's family have asked for donations to SILA or flowers for Ellie's funeral on 8th October.

Thanks are due to everyone who renews their subscription to SILA so promptly and who send

donations and offers to help.

Please continue to send in more Patients' Stories so that the next SILA Newsletter will have more pages than this one.

Lastly, I am sorry that Andrew Ferguson is no longer continuing as Assistant Editor of the SILA Newsletter and thank Andrew for all his help and support with past newsletters.

Heather Walker

Editor

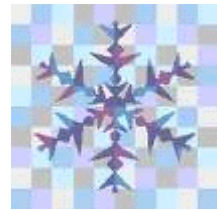
email: heather@sil.org.uk

SILA web-site www.sil.org.uk



SILA AGM

SILA's AGM will be held on Thursday, 8th October in the Boardroom of King's College Hospital, Denmark Hill, London SE5 9RS at 7 pm. All fully paid-up SIIA members can vote at the AGM. Afterwards there will be the usual support meeting.



Support Meetings are held at King's College Hospital on the first Thursday of each month except in August when there is no meeting. Enquire at the KCH Help Desk for the location of the meeting (usually the Boardroom). Meetings are held between 7 pm and 9 pm. Details of how to reach KCH are on SILA's website.

SILA West Midlands Branch. This branch is run by SILA member Mrs. Carol Bashford, 38 Yew Croft Avenue, Harborne, Birmingham. B17 9TR. Contact Carol: 0121 427 5462 or email her at carol_bashford@hotmail.com for information about any future support meetings, help or advice.

The Irish Sarcoidosis Support Group ISARC is at www.isarc.ie email info@sarc.ie Mary Walters is Chair of ISARC, telephone number 01903 872416.

Information received: Travel Insurance For People Living With Pre-Existing Medical Conditions

Freedom Insurance Services Ltd.,
Richmond House
16-20 Regent Street,
Cambridge CB2 1DB

Telephone 01223 454 290 Monday to Friday 8 .30 - 5.30 pm Saturday 9.00 am - 12 noon

www.freedominsure.co.uk email: information@freedominsure.co.uk Fax 01233 720 277

Bexley Accessible Transport Scheme Unit GO5, Thames Road, Cryaford, Kent DA1 5QJ Telephone 01322 31133 Provides transport services to Bexley Residents and members of community/voluntary groups and wheelchair users. Hop'n'Shop Scheme for those over 60, and those with a child under 5. This service is available for a membership fee.

Electronic version of the SILA newsletter: The SILA newsletter is placed on the Social Network site (<http://sarcoidosis.ning.com>), in Word format — in the Topic in Main Forum titled *Publication of the SILA Newsletter* — before being sent out as hardcopy. To access this, you need to join the Social Network. But at about the same time, an easily accessed pdf copy will be put on the SILA website (along with other backnumbers). This may reduce paper use, since some people are perfectly happy with an electronic version; please let me, Heather Walker, know if you do not wish to receive the hardcopy version.

Our web address. SILA's sole web address, is now www.sila.org.uk; the email address is heather@sil.org.uk

Annual Subscription to SILA is still £12 per annum. SILA welcomes comments and contributions to the SILA newsletter; also fundraising ideas or initiatives.

CONTENTS

PAGES 5 & 6 Walking for Health - Jane Carter

PAGE 7 Immune Signatures in Sarcoidosis, Tuberculosis and other Lung Diseases This is a longer version of the extract that first appeared in the SILA newsletter 26 Winter/Spring 2010. A £10,000 donation was made by SILA to this research. The Up-Date to this research follows on the next two pages.

PAGE 8 & 9 SILA Report Update September 2010

PAGE 10 Sila Noticeboard.

PAGE 11 GIFT AID Form for Guidance

Royal Free Hospital and National Institute for Medical Research
Sarcoid and other lung disease research team: Drs Huw Beynon, Chloe Bloom,
Marc Lipman, Anne O'Garra

SILA Report Update September 2010

Sarcoidosis is a difficult disease to diagnose - often taking weeks to months to confirm and commonly requiring invasive procedures to do so. Current treatment is imperfect. In addition, the cause of sarcoidosis remains unknown and there is little understanding of the disease processes which underlie it. To try and improve management of this condition, our study has taken an innovative approach to sarcoidosis research. We are investigating blood samples from people with sarcoidosis and other similar diseases such as tuberculosis (TB) – with which it can be sometimes confused.

Gene analysis technology, currently at the forefront of medical research, is being applied to these samples to compare the activity of the genes in the different patient groups. The pattern of gene activity that is unique to a particular disease can not only be used as a potential diagnostic test but also improve our understanding of why some people develop a disease and how the body responds to it. The research group carrying out this sarcoidosis project have already successfully used this approach in TB. The results of the TB study have just been published in the highly prestigious and influential journal *Nature** to much national and international acclaim.

To date, 13 sarcoidosis patients have been recruited into the current study. Six of these patients were not on treatment. The patients were all recruited at the Royal Free Hospital: 12 while attending the specialist sarcoidosis clinic (Dr Huw Beynon) 1 who was attending the TB clinic (Dr Marc Lipman). The patients are divided into those with 'active' disease and those with 'indolent/quiescent' disease. There are four patients in the active group. All the patients have disease involving their lungs, eight of whom also have another organ that is involved such as their joints, eyes, skin or liver. Two of the patients consented to repeat bloods tests after treatment had been commenced and their sarcoidosis showed good response. Twelve TB patients and 11 healthy controls have also been recruited. For the gene pattern analysis we need to recruit at least 15 patients into each of the 4 groups (active sarcoidosis, indolent sarcoidosis, TB and healthy controls).

To get the most from the gene analysis technology the ideal timing of the blood samples is when patients are symptomatic with active disease and not on treatment. Sampling can then be repeated once the patient has shown a good response to therapy. This allows us to hopefully detect a strong and unique gene pattern in the sarcoidosis patients; which can be distinguished from that seen in TB or other similar diseases. Furthermore this may be shown to alter in those subjects with a good response to treatment.

Collecting samples from patients at this symptomatic stage has proven challenging as most patients attending the clinic are usually already on treatment. Even though we are working within a specialist sarcoidosis clinic the disease is fairly uncommon in the general population and therefore new cases occur infrequently. This has led us to approach another specialist sarcoidosis centre, based in Oxford, to help with recruitment of active patients who are not yet taking treatment. We are hoping to have collected enough patients to process the samples by the end of 2010.

Later this year we will also be expanding the project to look at other lung diseases such as infectious pneumonia, to determine if the sarcoidosis signature bears any similarities to other conditions which have a rather different clinical presentation.

Apart from SILA's generous support, our work is also funded by the UK Medical Research Council, The Dana Foundation Program in Human Immunology and the US National Institute of Health.

We would be delighted to send you more a more detailed update, or to come and present some of our work at a meeting if that were helpful

*** *An Interferon-Inducible Neutrophil Driven Blood Transcriptional Signature in Human Tuberculosis.* Nature 2010;466:973-9.**

M Berry, C Graham, F McNab, Z Xu, S Bloch, T Oni, K Wilkinson, R Banchereau, J Skinner, R Wilkinson, C Quinn, D Blankenship, R Dhawan, J Cush, A Mejias, O Ramilo, O Kon, V Pascual, J Banchereau, D Chaussabel, A O'Garra

Immune Signatures in Sarcoidosis, Tuberculosis and Other Lung Diseases

The clinical features of many human diseases are influenced by the body's immune response. In some, the presentation directly results from either under- or over-activity in the immune system. As there are approximately 23,000 genes within the human genome, and many of these are related to immunity, it has proven difficult to investigate what is happening at the gene level. Recent, cutting-edge technology using microarrays, which measure the unique product released by every activated gene, now allows us to identify the patterns of gene activity that represent the human immune response. These patterns, which can be recognised with the aid of sophisticated software programmes and advanced statistics, provide an immune signature for different diseases. The information obtained from this enables us to start to determine which immune genes are associated with specific conditions.

Previous work with the infectious disease tuberculosis by Dr Anne O'Garra and collaborators has demonstrated the value of this approach. Now we are turning our attention to other diseases such as sarcoidosis, which appear to arise due to changes in human immunity. Not only are we using standard blood sampling, but also we are investigating what happens in the lungs of people with these conditions, as it may be that there are different immune responses at different sites of the body. Given that these diseases often involve the lung, we believe that this is an important approach to take. Part of our work, therefore, involves developing novel ways of safely, easily and repeatably obtaining lung fluid samples from subjects.

We believe that the information we obtain may help in the longer term to assist with diagnosis and monitoring; and also suggest new ways of treating these complex conditions (for example through using drugs that turn down immune genes that we detect to be over-active in patients).

Our work requires both scientific and clinical expertise, alongside the use of advanced technological tools and the recruitment of carefully-characterised subjects with different medical conditions, drawn from the clinics of the Royal Free Hospital. To plan this study Dr Anne O'Garra, a world renowned immunologist based at the National Institute for Medical Research, London collaborated with Dr Huw Beynon, a leading specialist in sarcoidosis and rheumatological medicine and Dr Marc Lipman, a specialist in tuberculosis and respiratory academic medicine. Dr Chloe Bloom is undertaking this as her PhD, and will be the main researcher on this project. She is funded by the UK Medical Research Council (who, following rigorous external review, only fund one in five such applicants). We have ethical approval from the UK Research Ethics Committee to run for five years; however we expect to continue this research for some time beyond this, as we discover more about this fascinating area of translational science and medicine.

Walking for Health, Jane Carter

Following my diagnosis of Sarcoidosis in December 2008, I was determined to face the illness in a positive way, by researching it, understanding my body more, and fighting it. I felt it would be a good idea to do something which raised money for Sarcoidosis, and in turn kept me fit as the steroids I was taking were causing me weight gain.

I had always hated walking when I was younger and remember dragging my heels and moaning when my mum took us out for walks. Now I'd realised that I actually enjoyed walking, alone, as it allowed me to take time out and think things through. It is also a free form of exercise and I am lucky enough to live in Bath where there is an abundance of opportunities for beautiful walks in amazing places.

I don't drive as I have never really fancied learning to and never really needed to. I remember looking at train fares online and thinking how expensive it was for me to travel to London to visit friends. I wondered how long it would take to walk to London? That idea stuck with me and I knew that the canal in Bath stretched all the way to Reading as I had been at University in Reading. I didn't know if the length of it was walkable though, so I started researching.

I decided that I would walk to London from Bath to raise money for SILA, figured it would take about 9 days so I booked 2 weeks leave from work and planned my training and started getting sponsorship. I mentioned my plans to my doctor and consultant and they were encouraging of it, despite joint problems early in my illness, my Sarcoidosis was only affecting areas of my body which weren't related to walking so I was lucky.

The walk was planned for early December 2009 so I decided I should book my accommodation well in advance as incentive not to back out! Friends and family thought I was crazy to want to walk alone for 9 days in December and many offered to accompany me for the odd day but I am a bit of a control freak and wanted to be able to do everything without compromise! And, if I am honest, I was really looking forward to being on my own for the walk.

Training was fun and took up all my weekends for months and I suffered from appalling weather throughout! This ensured I was fully prepared for my walk. I had all the wet weather gear I could possibly need, a map bag, a compass and a pedometer.

I was also raking in the sponsorship money and when it looked like I would raise £1000 I was delighted as this had been my target. My mum stepped into action and was gathering sponsorship form anyone who had ever known me from my 36 years on this earth.

My work colleagues were also pledging and in order to encourage them I stuck a map on the wall at work of my 115 mile route and that certainly helped people understand my challenge!

So, December arrived and I set off..within 5 mins of my house I can get onto the canal so very quickly I got into my stride and despite losing my pedometer

about 1 mile into the walk, that was it, I was in the right frame of mind and I was determined. I bumped into the nurse from my GP practice who had been so supportive and helpful to me over the years, having a walk herself around Bradford on Avon so I stopped for a quick chat and it felt like a good omen for me to have seen her.

I was on an high and even though it rained for the first few days, I was loving it. I stayed in Trowbridge (Busy hotel) and Devizes (Great Breakfast) and then Pewsey (Comfy bed which I slept in for about 11 hours!) and then the rain started to clear up and I moved on to Hungerford (where I had a fabulous curry), Newbury (Big Breakfast) and Reading (had a nostalgic but short wander round the town). After leaving the canal behind at Reading, I made my way to Windsor (Relaxing big bath) which was an interesting day as it involved proper field walking with stiles, this made a pleasant change from the straight route along the canal. It didn't last though as the next day I was back onto a canal at Slough which led me into Kew where I stayed overnight (didn't sleep well due to excitement) before my final half day walk into Paddington.

I was meeting some friends at Paddington to celebrate and one of them had made me a fabulous and massive 'medal' which I sat in the pub wearing with pride! I had completed a 115 mile walk and it had been hard. I'd had comfy beds to sleep in every night and some days had seemed like holidays. Friends had texted me along the way which kept my spirits up, and kept me up to date on the gossip of course. I'd had podcasts and the radio to listen to. And overall, I had really enjoyed my own company and I thrived on the independence.

Travelling home on the train took an hour and a half, which made my 9 days seem laughable! And yes, I could have walked quicker. But, I wanted to finish it and I wanted to enjoy myself! I couldn't have done it without the support of friends and family who texted me and sponsored me. I couldn't have done it as comfortably without my 2 pairs of Brasher walking trainers which I now wear everyday of my life as I am a total convert. I couldn't have done it without my Ordnance Survey maps and my 'Stuff you should Know' and 'Adam and Joe' podcasts.

I had walked 115 miles in 9 days and the final fundraising total came in at £1583.00. I was, and remain, delighted! Although I don't plan on doing anything this year, I am already thinking of something for 2011. A few wags have mentioned the Panama canal or the Suez canal which I laugh at but I have spotted a great Erie canal route going through New York State...(Don't tell my mum, she worried enough about me walking along the Kennet and Avon!)

