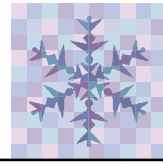


S.I.L.A NEWSLETTER

Sarcoidosis and Interstitial Lung Association.
SUMMER 2004



Dear SILA Supporter

I hope that as summer approaches after the torrents of spring, most people will have a chance to get away from home on holiday. I noticed from information sent to me that a consortium of 8 disability charities is launching a campaign to remind the travel industry of its legal obligation to provide fully accessible holidays after the Disability Discrimination Act comes into force in October. The Holidays for All Groups includes Action for Blind People, Holidays with Help and Leonard Cheshire www.holidaysforall.org.uk I have had a letter from a SILA member who writes on RNIB writing aid to say that she has sarcoidosis for ten years and because of heart trouble has had no treatment, but has been put on a gluten free diet. This member has a guide dog called Tara who is seven and a half years old who is her best mate. But she tells me, she has to keep smiling and refuses to give in. So I think that this is a positive message even if the prospect of a holiday or a break is not on the immediate horizon. It seems that something is being done to make holidays more enjoyable for those with disabilities, even if it needs legal backing. Another useful web-site is to be found at www.accessiblecitybreaks.co.uk. And www.accessiblecruises.co.uk. They have links to other site for the disabled and cover almost any destination in the world. We welcome feed-back from this newsletter, so I hope to hear from you to air your comments, suggestions etc.

I hope that everyone can enjoy a break, however brief, this summer.

All good wishes



Heather Walker

EDITOR

SILA UPDATE

March 30th 2004 Heather Walker and Daisy Anderson were interviewed Anthony Davis of the Deptford Community Radio Project, London SE14. The DCRP is funded by the Healthy Communities Fund to promote healthy communities in Lewisham and has a regular slot on Resonance 104.4 FM and attracts 50,000 listeners every month, across central London and Lewisham, and on the web. The radio interviews about sarcoidosis and SILA were pre-recorded and went out on Wednesday 14th April and Wednesday 21st April at 4.45 pm.

INFORMATION RECEIVED

Cathy Read, Respiratory Nurse, UCLH is no longer recruiting people for sarcoidosis research, but results of the research will be published in the next few months. There was no longer any funding to keep the project going. Cathy is now working for a consultant who specialises in early lung cancer detection. The information about sarcoidosis research in The Patient Information Booklet therefore no longer applies. Sincere thanks are due to Cathy for all the help and advice she has given to SILA supporters in the past.

Sent from the Internet

For any sarcoidosis (or other lung disease) patient who is awaiting lung transplantation or contemplating one in the future, the following book :TAKING FLIGHT will be of interest. The book consists of 255 inspirational stories of successful lung and lung/heart transplantations around the world. The first ever book on this subject.

To read excerpts online, go to:- <http://www.trafford.com/robots/02-0497.html> published by Trafford publishing ISBN 1-55369-684-0

Joanne Schum
luckylungsforjo@aol.com
Home info:
1104 Bay Road
Webster, NY 14580
USA

Support Meeting At King's College

Meetings from 7pm-9pm on the 1st Thursday of every month, except August. All are welcome. Patients, Partners, Family and Friends



S.I.L.A NEWSLETTER



A Patient's Story

I first noticed the lumps on my legs whilst we were on holiday visiting my aunt on her smallholding in Yorkshire; I put them down to a by-product of playing with the sheep and ducks and thought no more about it.

I had been diagnosed as asthmatic some years earlier; it was usually well controlled – but now I suddenly found myself desperately short of breath; even speaking could cause a dreadful coughing spasm. Falling asleep was suddenly the order of the day – I would sit down to read my library book, and wake up minutes or even hours later. And then one morning, I found that getting out of bed was just impossible; shoulder, elbow, wrist joints had all apparently seized up over night. My ankles were twice their normal size – clearly a visit to the doctor was in order. I came away with a moderately strong pain killer and a steroid inhaler.

A week later, desperate by now, a further doctor's visit, this time to a very thorough lady doctor; and this time I rather diffidently mentioned the lumps on my shins. 'ah yes,' she said. 'erythema nodosum. I think I know what your problem is'. A round of x-rays, blood tests, ct scan and finally (horrors) a bronchoscopy followed to finally confirm a diagnosis of sarcoidosis.

I was granted an interview with a very superior consultant; after a cursory exam, and a quick glance at the results of my numerous tests, he said (yes, you've guessed it!) 'Well, there is really nothing to worry about. It'll go away in a couple of years. Just live with it.' I was dismissed.

What his supreme haughtiness didn't mention (and probably didn't know) was that it comes back. Not in the same form, of course. It's sneaky like that. A shoulder joint went next, accompanied by an extraordinarily nasty back pain. This was followed in rapid succession by double vision and dry eyes; high blood pressure; a couple of nasty skin eruptions, disturbed liver function and latest and by far the best, chorioretinitis and swollen optic nerves. And this time, the steroids.

Let's be fair, the steroids probably saved my sight. They very nearly lost me my marriage. The mood swings were horrendous, the weight gain disgusting (up at three in the morning gobbling mars bars). The bullfrog neck reduced me to tears, as did the grossly swollen stomach. It was truly distressing. The good news is that all of these things have now gone away; (the weight admittedly still has a way to go). I have a permanently weak left arm; my skin tends to break out every so often and looks disgusting, and I have lost much of the colour vision in one eye and now need to wear spectacles. But most of the time, I feel well. I get on with my life.

After twelve years of living with the disease I have decided that the only way to live with it is to go along with it – if I am tired, I go to bed. If I am sore, I take a painkiller. If I have symptoms that are worrying I go to visit my (very kind) G.P. He admits he knows little about the disease but at least he is willing to listen and try to find out what is happening. I despair sometimes at the ignorance surrounding the disease. It is time the medical professionals were made to sit up and notice us. There are a lot of us out here. SM.

Information Received

FREE DIRECTORY ENQUIRIES

A free directory enquiries number for disabled people is available. Anyone who cannot hold, handle or read a phone-book, can use a free BT 195 service. Fill in a application form and provide evidence of your disability. For registration, telephone 0880 587 0195

BOOK SALE FOR SILA

SILA member Allison Ainsworth, Northwich, organised a bring and buy book sale at her workplace and raised £72 for SILA. Many thanks again to all who contributed

All correspondence should be addressed to:-
 The Secretary, SILA
 Chest Clinic Office
 2nd Floor Admin Block
 Kings College Hospital
 Denmark Hill
 London SE5 9RS
 Email: info@sarcoidosis.org.uk

A video regarding Sarcoid is available from SILA, with a returnable deposit of £20.

Subscriptions to SILA remain at £12 p.a. please renew subscriptions promptly.

SILA AGM 2004 will be held on Thursday, September 2nd in the Belgrave Room, King's College Hospital, Denmark Hill, SE5 at 7 pm All fully paid up members will be eligible to vote