

**SUMMER
Newsletter
2008**

**DORSET LUPUS
GROUP**



Committee

Chairperson: Margaret Hosking
(Tel: 01202 884809)

17 Minster View, Wimborne,
Dorset. BH21 1BA

Secretary: Responsibilities
currently being carried out
temporarily by Margaret Hosking
until the position is filled

Treasurer & Vice Chair: Debbie
Steel, 7 Ebor Close, West
Parley, Ferndown, Dorset. BH22
8LZ

Newsletter Editors: Margaret
Hosking & Debbie Steel

Raffle: Carol Berkhauser

Librarians: Yvonne & Guy
Hosking

Membership Secretary:
Gerrish Gray

Other Members:
Jayne Baker

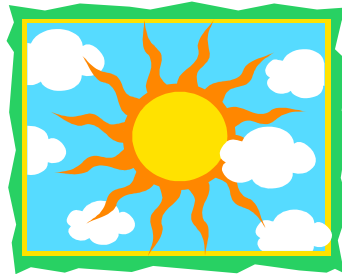
Shirley Merrett

Janet Bourne

Yvonne and Charlie

Contacts

Margaret Hosking 01202884809



Welcome

It was lovely to meet up with so many of our group at the coffee morning held in February at the Sandbanks Hotel, Poole. We filled the lounge until it was overflowing and there was much chatting and laughing.

This was followed by the AGM at the beginning of April where we had a record number of attendants, who included several new members and a few members who had been too ill to come along for some time. It was so nice to see you all. Chris Maker, the Director of Lupus UK, joined us for the meeting and Carole Frosdick, the new Lupus Practitioner at Christchurch Hospital, told us about her work with Lupus patients.

More recently I would like to pass on my personal thanks to Frances, James and Maddie, who offered us their home in West Melbury, as a venue for a Saturday Coffee Morning. This enabled several of our members, who would not normally have been able to travel to such an event, the opportunity to come along and meet others. It all went very well including the home baked cake!

We have arranged a variety of events for this Summer and hope that you will all bring your

family and friends along too. It's good to meet others and realise that you are not alone with Lupus.

If you need transport for any of these events we will always try to help. Please phone me on 01202 884809

We also aim wherever possible to ensure that all our venues are suitable for wheelchair access with adequate parking.

Margaret Hosking

Membership

Membership renewals were due at the beginning of the year and the renewal forms were included in the last News and Views.

Please will you check whether you have rejoined. It is so easy to let things slip your mind. If you have mislaid your membership form we have got plenty of spare ones.

The membership subscriptions due on 1st January were £8.00 (single) or £14 (2 people at the same address). Payment by cheque/postal order should be made to payable to "Lupus UK" and sent to Lupus UK, National Office, St. James House, Eastern Road, Romford, RM1 3NH.

Contacts



Contacts are friendly, helpful and understanding people who have

offered their time to chat to anyone about Lupus. There are times when you may need some information and times when you feel just a chat may help you. There is no need to sit at home and worry. Just pick up the phone.

Hospital Buddies

Recently we were asked by a member if one of us could attend their hospital visit with them, merely as a listener, to support them. The appointment went well and it led us to wonder whether anyone else would find this form of "help" useful? Would you like to have a second pair of ears to help remember all that the doctor has told you?

We have formed a group specifically for this purpose and would like to hear from you. Please contact Margaret on the number at the beginning of this Newsletter and she will be happy to make the necessary arrangements.

This will, of course, be highly confidential and at no charge to any of our members.

Trust Fund

You may recall that we received over £2,000, kindly donated by the Dorset Lions as a result of a half marathon. This was donated to Dorset Lupus Group specifically for the benefit of their members.

The Trust Fund is now up and running and will be overseen by 3 committee members. It has been decided that funds may be released for a variety of financial needs. We are all aware that having Lupus can be expensive. You may need help with equipment, travel to the Specialist, accommodation etc – the list is endless!

Initially we would like to help up to a maximum of £50 but each case would be considered on its own individual merits.

To apply, please write to Margaret or Debbie with the details. Strict confidentiality will be followed at all times.

World Lupus Day May 10th

Our members in North Dorset have arranged to have a Table Top Sale in Sherborne's main shopping centre in aid of Lupus, to raise funds and create general awareness. The full address is

**Parson's Pass, Cheap Street,
(next to the Butchers)**

They will be there from 10.00am onwards. Our good wishes go out to all those members. If anyone is in the neighbourhood, perhaps you could go along and support them? If you can help with any donations of cakes etc, I am sure they would be very appreciative. Please call Sheila Rossiter on 01935 814339.

If anyone else does anything to note World Lupus Day, could you let me know so that I can mention it in the next Newsletter?

Lupus UK Convention, Glasgow, May 11th

Debbie & Dave will be attending and will bring back a Report for the next Newsletter. Carole Frosdick will also be there so between them we should have a few highlights to recount!

Forthcoming Events

GARDEN VISIT AND AFTERNOON TEA



**Saturday 21st
June 2.00-5.30
NOTE REVISED
DATE**

We have been offered the opportunity to visit a garden listed in the NGS (National Garden Scheme) "Yellow Book" for a private viewing and afternoon tea. It is at Oakdene, Sande Heath SP6 1TD, approx 1.5 miles west of Fordingbridge an adjacent to St Aldhelms Church. Entrance is £3.00 (children free), cram eas extra.

We will be having a Raffle – proceeds to Dorset Lupus.

I hope you will all be able to come along as the garden looks wonderful and even Joe Swift of Gardener's World commented on the teas! There is ample parking and all is accessible for those with mobility problems. There is also a conservatory in case of rain.

For those with internet access and online map can be on at

<http://www.multimap.com/maps/?title=Oakdene&hloc=GB|SP6%201TD>

SKITTLES EVENING



**Friday 27th June
from 7.30p.m. Colliton Club,
Dorchester**

Chris McKenna has organised a fun evening for us at The Colliton Club, Colliton House, Colliton Park, Dorchester D1 1XJ. The address will be familiar to many of you because Dorset County Council offices are immediately adjoining on Colliton Park. The

cost will be £5.00 for Sausage, Chips and bowling or

£6.50 for Scampi, Chips and bowling.

(if you would prefer an alternative menu perhaps you could contact Chris directly on 01305 848629?

Older children are welcome. Parking and wheelchairs are no problem. There is a lovely new outdoor patio for those who wish to eat "al fresco" but let us know beforehand as we will need to have an idea of numbers). There will be a cup for the winner! We will also hold a Lupus Raffle.

Please send your cheques payable to "Dorset Lupus" and menu choices to Debbie Steel.

Bring along all your family and friends to make this a fun packed evening.

SUMMER "LUNCH 4 LUPUS"



Sunday 27th

July from 12.30p.m onwards

Another great party hosted by Debbie & Dave following on from last year's success with the **Ploughman's Lunch**. There will be a choice of menus (including a Ploughman's) and the cost will be £7 per head including dessert. Let's see if we can make this a great fundraiser, and have a good time as well! There may also be some good news to celebrate, whether Margaret's daughter's twins are due about then. There will be the usual Raffle and a Quiz or two, so bring along a little spending money and **all** your friends.

Could you please phone Debbie on 01202 877390 and send cheques payable to "Dorset Lupus" by 13th July. Don't forget – it will go ahead whatever the weather!

COFFEE MORNING



Saturday 23rd

August 10.30a.m-12.00

At the Howard Centre, Christchurch Hospital.

Usual library, raffle etc. Friends and family welcome.

There will also be a Coffee Morning in Milborne Port later in the year – more information later.

Sponsored Walk

In October, as you may recall, we generally do a Sponsored Walk to raise awareness about Lupus. It only needs to be a short walk – the distance is not important. We are merely trying to spread the word, and raise some monies at the same time. If you would like to come along, whether sponsored or not, please contact Debbie. We plan to walk on Saturday 18 October and would ask everyone to consider where we may be able to walk to get the most attention! Any suggestions for venues (not too long a walk).

Perhaps you could twist your friends' arm to get them involved as well.

Photosensitivity

If you suffer from light sensitivity, we have found a product that will help make your clothes more ultra violet resistant. If you wash your clothes in a final rinse conditioner obtained from www.suninsight.com, it will help protect you from the sun's rays. The cost is £10 for 3 packs.

A company called SunSibility offer a range of clothing which

also helps protect your skin. If you would like to order a brochure, you can contact them on 0208 224 0834.

Withdrawal of Light Bulbs

Some Lupus patients are affected both by ultra violet A & B light. At least 30% of people with lupus have light sensitivity problems, which can cause an immediate skin reaction.

By withdrawing incandescent light bulbs, at home and the workplace, may mean that certain people will be unable to work anymore because of the effects of the ultra violet light on their health. The light can cause migraine, extreme fatigue, dizziness and aching joints, not to mention the damage to the skin surface that affects many people. Does this act against people's rights under the Disability Discrimination Act?

The introduction of lighting to shops and public places may mean a fall in customers or problems with visits to hospitals, libraries, schools. The list is endless.

SPECTRUM, a group set up for those with light sensitivity problems, is fronting the campaign to stop the Government banning and reduce the impact of replacement lighting. LUPUS UK is also working with them and others too.

Spectrum now have a new Co-Ordinator, David Price, who has already sent emails to most, if not all, MP's to highlight the problem. There has already been 1 petition with 640 signatures which he is following up on to the PM, DEFRA and the Health Dept. He has also made representations to an EU meeting in Brussels, a DEFRA meeting in London and has now contacted Dr Havas in Canada

regarding her tests on LEDS. Needless to say they are awaiting the results of tests and much work is going on "behind the scenes". If anyone would like to know more, their website is www.spectrumalliance.org.uk.

Used Postage Stamps

Several members have collected used postage stamps. Keep them coming! There is no need to peel them off the envelope - just tear around the stamp carefully (as torn, damaged, incomplete and creased stamps are of no value) and bring along to the next meeting or send in an envelope. These stamps are sent away and funds are made for Lupus. We would like to have more stamps collected and handed to me. Perhaps you know some one who works in an office or some friends that would collect for us. At the last count, I sent almost 3500 stamps since Christmas!

Clinical Trials

We have received a letter from Sarah Cole, a Clinical Research Nurse, explaining that the Clinical Trials Unit at the Royal National Hospital for Rheumatic Diseases in Bath is currently looking for participants for a variety of studies, one of which includes a Lupus study. If you are interested in finding out more about the opportunities being offered, please contact Sarah direct:

Sarah Cole, Clinical Research Nurse, Clinical Trials Unit, Royal National Hospital for Rheumatic Diseases, Upper Borough Walls, BATH, BA1 1RL

Tel:01225 465941 ext 358

Fax: 01225 473405

Email: sarah.cole@rnhrd.nhs.uk

Recipe Corner

Unfortunately we have not had any suggestions for this letter. If you have any quick, easy recipes that we could include in our newsletter please send them to Margaret Hosking 17 Minster View, Wimborne Dorset BH21 1BA.

If you have any experiences, helpful tips, jokes or puzzles that could be included in the next newsletter please send them in to me.



How about writing down some of your childhood memories'?

Hope to see you all soon.

Debbie

Finally, on a lighter note,

Joke

A small boy is sent to bed by his father. Five minutes later.

"Da...aaaaad"

"What?"

"I'm thirsty. Can you bring a drink of water?"

"No. You had your chance, now lights out."

A little later "Da...aaaaad"

"WHAT?"

"I'm THIRSTY."Pleeeeeease can I have some water?"

"I told you NO. If you ask again I'm going to have to come in there and spank you"

After a thoughtful pause.

"Da...aaaad, when you come in to spank me will you bring me some water?"

North East Dorset Group

Here are the dates for your Notice Board



Dates For Your

Diary



May 10th World Lupus Day

May 11th Lupus UK Convention, Glasgow

June 21st Afternoon Tea and Garden Visit

June 27th Skittles and Meal

July 27th Summer Lunch4Lupus

August 23rd Coffee Morning, Howard Centre, Christchurch

October 18th Sponsored Walk