

**SPRING
Newsletter
2009**

**DORSET LUPUS
GROUP**



Committee

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Contacts

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details and she will get back to
you



Welcome

Dear Readers

I hope you have shaken off all the winter coughs and sneezes and can look forward to the Spring. My snowdrops and crocuses have been out for a long time and the daffodils are well on their way. It makes me feel good.

Many of you know that my health took a downward turn so I had to ask Debbie Steel to act as chairperson for our Dorset Lupus Group. She has made a wonderful effort as have the committee. I thank you all.

At the A.G.M. I am going to step down from my role as Chairperson. I have been on the Lupus Committee since the seventies when the Dorset & Hampshire Group was initially formed under the inspiration of Cheryl Marcus. I have served many years as Chairman and feel the position should now be held by someone else.

I thank you for all your support and hope I can work for the group as a "carer". The role of "carer" is to welcome new

members and to be a telephone contact for anyone who needs someone to turn to for a friendly chat and support when required.

I wish you all well.

Margaret Hosking

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.

In a previous Newsletter we also introduced the **Hospital Buddy** service, where a member of the Group would be happy to come along to any appointment or test at the hospital to help support you.

Please contact Margaret on the number at the beginning of this Newsletter if you would either like someone to come along with you (on a confidential basis of course) or to volunteer to help others in the Group.

We would not expect anyone to pay for this help and would be happy to cover any out-of-pocket expenses such as petrol or parking for the Buddy.

Following on from our last Newsletter, Smiley (aka Yvonne) has written a few lines to remind how important it is for all of us keep an eye out for one another especially with all this bad weather and cold about.

“GREETINGS EVERYONE,

There have recently been several of our members suffering for one reason or another this winter. If you know of anyone who is going through a bad time or who is in hospital or struggling at home please notify me so that I can send them a card, on behalf of Dorset Lupus Group, to let them know we are thinking of them. My email address is

smiley.face@sky.com

Alternatively phone me on Bournemouth (01202) 535123. It's always nice to receive a card.

Also I need more birthday dates so we can keep in touch on your birthday. Don't worry about the year, just the day and again I will do my best.

Thank you, take care everyone
Smiley”

Trust Fund

Remember, we have £2000+ to spend! Now that the credit crunch is here, we all have to tighten our belts even more. The Dorset Lions have donated this money to help and we are itching to spend it!

At last, we have been able to help someone. One of our members applied for help with the cost of running their electric scooter – we paid £50 towards the cost of a replacement charger. It gives them the independence to get out and do things on their own and I am so glad that we were able to help.

If anyone else would like to speak to me confidentially, to see whether Dorset Lupus would be able to help, please call me, Debbie, on 01202 877390 or write to me at the address at the top of the letter. Strict confidentiality, of course, will be followed at all times.

REVIEW OF PAST EVENTS

COFFEE MORNING MILBORNE PORT SEPT 27th

Janet Heath had kindly organised this Coffee Morning for us and as usual there was a warm welcome for all of us that had travelled so far. It is always nice to come and visit such a pretty part of the County.

The new Lupus Sales Catalogue had come out, so we all got a chance to see the new Christmas Cards and plan ahead. Including a £25 donation, we raised just over £101 from the Tea, Raffle and Christmas card sales.

Thank you Janet.

SPONSORED WALK FOR “GO THAT EXTRA MILE” POOLE PARK OCT 19TH

In October, as you may recall, we generally do a short Sponsored Walk to raise much needed funds and to raise general awareness about Lupus. This year we decided to walk in Poole Park around the lake and cricket pitch, a total of approx 1.5 miles on level ground all the way around.

In the end 17 of us walked, plus 3 dogs and Pat did admirably in the Information Stand by the Cafeteria, raising over £56 in donations and Lupus sales single handed!

It was rather cold, but at least the rain held off, a miracle by our usual standards. I have noticed that other groups are actually walking earlier in the year and I think maybe that might be the way forward so that we can all enjoy the walk in reasonable weather. So much for “The Sunny South”!

We nearly made it on local TV as a film crew was there filming some large model boats, with men paddling along inside them. We were told to stand at the side of the lake and watch the boats so we could be included in the shot. Despite taping South Today for the next 2 weeks we never appeared....

A number of our photos have been sent to News and Views so look out to see if you recognise anyone in them. I shall be bringing along all the ones taken to show at the AGM as well.

In conclusion we raised £267.64 in sponsorship, plus a further matched donation of £148 from Barclays Bank, thanks to Marcia Gray and all her family. Well done John, Michaela, Molly & Fifi the dog. In addition a lovely gentleman also sent us a further £10 donation afterwards, as a result of a chat we had with him around the cricket pitch during the walk.

Well done everyone.

Who fancies another walk, in the snow maybe?

“WIMBORNE IN BLOOM” TABLE TOP CHARITY SALE NOV 8th

This was not as successful as the last time we tried it – I am not sure why but I think maybe if we made more craft items and relied less on Lupus Christmas Cards, we may be more successful. However we did get our faces out there and that is as important as raising funds for the charity.

We thought maybe we would try this on alternative years in

future, with a bit more preparation. If anyone can offer some help making Tags for presents, or Table Decorations, or handmade Christmas Cards, or homemade Christmas Cake etc they would be very welcome. I can provide some storage, within reason, of course.

Despite this we still managed to raise just under £50 but that meant 11 of us manned the stall for varying periods throughout the day.

CHRISTMAS COFFEE MORNING, CHRISTCHURCH DEC 13TH

The spirit was definitely festive, even though we never managed the mulled wine. With Christmas Crackers and hats, and plenty of mince pies, sausage rolls etc, the coffee morning went along with a bang.

Even the Christmas themed Raffle went well. It was difficult to choose your gift as they were all so carefully wrapped with ribbons and bows; it seemed a shame to open them straight away. In fact quite a few of us took them home to stand under the Christmas tree with all the other gifts ready for Christmas morning.

Pat made some beautiful Table Decorations, which went so quickly that I must have under priced them. They were lovely and mine is still on my hearth at home brightening my fireplace. Thank you Pat! That was a fantastic gesture, and earned us another £15 in the kitty!

The mood was bright and the event was well attended and set us up nicely for the Christmas festivities ahead. Altogether we raised £60.

Thanks to all the Committee who donated the food etc and to everyone else for coming along and having a good time.

SUNDAY LUNCH AT THE MIRAMAR HOTEL, BOURNEMOUTH. JAN 18TH

The day was beautiful, the venue perfect as we squeezed 27, plus 2 babies, into **The Library**. The food was excellent and I believe everyone had an enjoyable time. The children were so quiet; we barely knew they were there. The sun streamed in and it was so hot that the blinds were half pulled down and the windows opened slightly to let the cold breeze in. Feedback from everyone was favourable and we may well use them again for something in the future.

FORTHCOMING EVENTS



COFFEE MORNING AT THE HAVEN HOTEL, SANDBANKS, BH13 7QL on Saturday 14th March at 10.30a.m. to 12.30p.m

We shall be meeting in the Brownsea Room, overlooking the sea and the ferry at the end of the Sandbanks peninsula – a nice place to relax, look out at the sea and dream. Unlike last year (when we tried **The Sandbanks Hotel**) we shall have a whole room to ourselves with plenty of room to spread out and chat. Tea or coffee will be £2 each, as will the miniature pastries served as well. Not quite as expensive as last year, and this time we will get the view too! There is also a sun patio if the weather is kind to us.

Disabled access and toilets are available. When parking, go through to the rear car park as it is easier to get in. If anyone needs a lift please call Debbie, who will arrange transport.

We shall hold the usual raffle, so would welcome any prizes you may bring along with you. Hope to see you all there.



A.G.M. AT THE HOWARD CENTRE, CHRISTCHURCH HOSPITAL Saturday 4th April at 10.30a.m. for the official business to start at 11.00a.m.

This year we are hoping to have Dr Hopkinson (not confirmed) to talk about any recent developments in Lupus. We will also have a visit from Tina Stemp who is not only the new Treasurer of Lupus UK (replacing Tony Rance), but also the Chairman of our neighbouring Lupus Group – Hampshire. Both will take questions from anyone and it would be nice if everyone could come along and meet them.

As our Christmas Coffee Morning worked well, we thought about having an **Easter Theme** this time. Please do not all dress up as bunnies.....! We aim to have Easter Biscuits and Hot Cross Buns with our teas. As always, there will be a Raffle. It would be lovely if we could keep the theme going but don't worry if not, as all prizes are very welcome.

In addition to the Raffle, following the success of our Chocolate Quiz a couple of years ago, I have a Sweetie Quiz. The questions are listed on the back page of this Newsletter. It will cost £2 to enter the competition. All I need is your answers on a postcard, letter or email (or at the A.G.M.) and the winner will win a large Easter Egg. Good luck!

For the A.G.M. we will be reviewing the year and electing a new Committee. Could all those existing members who would like to remain, please contact me beforehand so that I can incorporate that into the minutes. For anyone else who is interested in joining the committee could you also contact me by telephone, email or letter?

We are always keen to incorporate new blood and new ideas. I am conscious that we have no one on the committee who has a young family, or who lives outside the Bournemouth conurbation and it would be helpful to have a more representative committee. Even if you can only spare a little time, we only meet 3 times a year, at a venue that can be moved to suit everyone.



**QUIZ NIGHT AT
HAMWORTHY ENGINEERING
SPORTS & SOCIAL CLUB,
Magna Road, Canford Magna,
Wimborne, BH21 3AE on
Friday 1st May at 8.00p.m.**

We are planning to host a Quiz Night to raise as much money as we can, and have some fun whilst doing it! The room at the Social Club is now booked. It will take up to 100 people, and we would now like to ask you to encourage all your friends, colleagues and family to come along and join in. It has full disabled access and the room is right next to the bar. There is also plenty of parking available.

I now have some posters but need help putting them up – hospitals, libraries, notice boards, schools etc HELP! I have plenty so if you can help with this please call me. Unfortunately I do not have enough to send to everyone who receives this letter but have about 100 in total.

The only way we will make money will be to widen the distribution of adverts. Does anyone have any contacts in the media or ideas where this should or could be advertised?

Teams can be up to 8 (although the more in the team, the less you win). First prize will be 25% of ticket sales and players will pay £2 each.

There will also be a raffle. We would like to offer larger, more expensive items as the ticket price will be higher so if you can donate anything, or could talk to any local companies or businesses that may be able to help, please call me. I can send them an official letter (as this is usually needed). We already have a meal for 2 donated from "The Nightjar" to get the ball rolling.

Please help support us with this one.



**LUPUS UK
CONVENTION AT THE BEST
WESTERN, STOKE-ON-TRENT
MOAT HOUSE, ST1 5QB on
Sunday May 10th at 9.00a.m.**

As usual this promises to be an excellent event. I have looked into the cost of providing a mini bus and unfortunately I was quoted £375 for one with a driver for the whole of Sunday. Unless this was fully utilised (seating 16) I am not sure we can justify the expense. I can however confirm that there are often members going, and I for one will be happy to give someone a lift, if they want to travel on the Saturday, and stay overnight. Please contact me if you are interested or if you are also able to offer a lift to someone.

The cost is £15, which includes teas/coffees and lunch. From experiences the talks are always interesting and well worth the effort.



**COFFEE MORNING
AT THE NIGHTJAR, Canford
Cliffs on Saturday 16th May
from 10.30a.m.**

The Nightjar will be hosting the next Coffee Morning in our busy schedule and they will be

advertising locally. For those new members, The Nightjar is a restaurant/pub who is sponsoring Dorset Lupus. They have twice weekly Quiz Nights, on Wednesdays and Sundays, and a collection tin on the bar and to date have raised **over £474** since our connection started in October 2008.

We hope to bring along some nice cakes, so if anyone could help with this, could you let me know. There is plenty of parking and easy disabled access to the building. Hopefully the weather will have improved and we shall be able to make use of the garden facilities. If not, then there is still plenty of room outside.

If anyone is interested but needs help or transport please call me on 01202 877390 and I am sure we will be able to assist.



**MANOR FARM,
HAMPRESTON, BH21 7LX on
Sundays May 24th, June 14th,
and July 19th at 2-5p.m.**

Anne Trehane is opening her garden on the above dates under the National Garden Scheme and has kindly offered to donate the sale of teas and cakes to Dorset Lupus.

In the Yellow book the garden is described as "A traditional farmhouse garden designed and cared for by 3 generations of the Trehane family. It is now being thoughtfully replanted with herbaceous borders and rose beds within the box & yew hedges. It also has a mature shrubbery, water and bog garden."

If you are able to help serve the teas and coffees please call me as we need volunteers – probably 3 each Sunday. Even if you can only offer an hour or two, it would be lovely to see you. Alternatively if anyone is interested in visiting, by having a

cuppa as well, you will also be helping support us.

Thank you, Anne for your generous offer. Let's hope we have some lovely weather.

Newsletter Article

Carole Frosdick has kindly written an article about the ANA blood test that a lot of us have on a regular basis.

“ANA stands for **Anti-nuclear Antibodies**. They are the antibodies within our system and can attack the contents of the cell's nucleus. They are present in much higher numbers with an autoimmune disease, such as Lupus.

The test measures the pattern and amount of the antibodies which could attack the body tissue as if it were foreign matter, rather than defend it.

In 1948 Dr Malcolm Hargreaves, from America, discovered the **LE cell** in the bone marrow. The cell is essentially a white blood cell which has engulfed the nucleus of another cell. Over the years more sensitive tests were developed enabling SLE (Systemic Lupus Erythmatosus) to be recognised in milder forms through a simple laboratory blood test. Previously diagnosis depended on a test of tissue specimens!

ANA is measured in units of **titre** and anything in excess of a titre of 1:40 would indicate an autoimmune disease is present. The presence of ANA is indicative of SLE in 80-90% of cases. It is also evident in cases of Sjogrens, Rheumatoid Arthritis, Autoimmune Hepatitis, Scleroderma, Polymyositis, Dermatomyositis and others.

Approximately 5% of patients with SLE do not demonstrate the antinuclear antibody and LE cells are referred to as ANA negative lupus. These patients are more likely to have rashes, Raynauds,

photosensitivity and serositis. They have subsequently been found to have a different antibody – antiRo(SS-A).

As a footnote, a USA based arthritic pain cure centre has discovered, when studying twins, that if one gets lupus the other is much more likely to get it too if they are identical twins (i.e. share the same genetic make up) rather than fraternal twins (where they do not have the same **genetic** make up) or siblings. Surely this is compelling evidence that there is a genetic aspect to the disease.”

Used Postage Stamps

Many of our members are regularly collecting used postage stamps. Please 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 them along to the next meeting or send them to me in an envelope.

Since our last Newsletter, I have sent a further 8,667 to Lupus UK which means a total of 16,987 stamps for 2008 and 2680 so far for 2009!

Diana Westrip explained why we are collecting them and how we make money on them as follows

“Initially I check for damaged, creased or ripped stamps and take them out as they are not worth anything. I then sort them into

- Everyday definitives
- Commemorative
- And Foreign

I also take out anything that I think may be worth more individually and consult a professional. Albums or collections are also sold to a dealer, who is fair, honest and

trustworthy. All the stamps are then sold and I get a cheque payable to Lupus UK.”

Recipe Corner

Unfortunately I have had no suggestions for this newsletter.

If you have any quick, easy recipes that we could include in our next newsletter please send them to Margaret Hosking 17 Minster View, Wimborne Dorset BH21 1BA.

OR

If you have any experiences, helpful tips, jokes or puzzles that could be included in the next newsletter please send them to me. How about writing down some of your childhood memories'?



I hope you have enjoyed this Newsletter. The next one will be coming out for the summer period, when we shall have our new Committee! If anyone has an article they would like to have included could you please contact me for the cut off date for the next Newsletter.

I would also ask that if anyone is interested in helping, or even taking over, the Newsletter please come forward. It is becoming very difficult to continue with it whilst carrying out my other responsibilities and I would welcome any help offered. If someone was prepared to take over the Editorial, I would be more than happy to help them should they wish it.

In the meantime, I hope you are all as well as can be expected and look forward to seeing you at the coming events. Take care

Debbie Steel

FIND THE SWEET

All the answers are well-known sweets. To make it easier I have given the number of letters in each answer. All answers to be posted or emailed to D Steel correspondence addresses or brought along to the A.G.M. with your £2 entry fee. All proceeds to go to Dorset Lupus. The winner will receive a **Special Easter Egg**.

1. Not practised by white witches.....(5,5)
2. Alfresco Meal.....(6)
3. Little wobbly infants.....(5,6)
4. Hockey match on horseback.....(4)
5. A gift or reward.....(6)
6. Trim seas badly in a variety of colours including blue.....(8)
7. Roll a ball and bowl them over.....(8)
8. Fourth Rock from the Sun.....(4)
9. All sorts without the trimmings.....(9)
10. I'll fuse traps it.....(5,9)
11. An independent system of stars held together by a gravitational attraction..... (6)
12. You may want to give these to your loud mouth pal.....(10)
13. Later mess?.....(9)
14. Slightly larger than 4.....(5,4)
15. King of the Jungle.....(4,3)
16. Find this man on a race course.....(3,3)
17. The card game of pontoon.....(5,4)
18. Old fashioned wandering musicians.....(10)
19. Luminous band stretching across the night sky.....(5,3)
20. Initially an elephant running off..... (4)

(Thanks to Hampshire Group for the Quiz.)

Finally, as a reminder, here are some dates for your Notice Board

Dates For Your Diary



Mar 14th – Coffee morning, The Haven Hotel, Sandbanks

April 4th – Annual A.G.M.

May 1st – Quiz Night at Hamworthy Sports Engineering Sports Club

May 10th – Lupus UK Convention, Stoke-On-Trent

May 16th – Coffee morning at The Nightjar

May 24th, June 14th and July 19th – Open Garden at Manor Farm, Hampreston