

# DORSET LUPUS GROUP

## Newsletter (Sept 2005)



### Committee Members

**Chairperson:** Margaret Hosking  
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**Vice Chairperson:** Jayne Baker

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**Treasurer:** Ian Brittain

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**Raffle:** Carol Berkhauser

**Librarians:** Yvonne & Guy  
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**Other Members:**

Gill Green

Shirley Merrett

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Janet Bourne

**Contacts:**

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### Introduction

Hello everyone. I hope you are all feeling happy and have enjoyed the summer months. We have had some lovely get-togethers which have given people time to get to know each other. The open air jazz at Kingston Lacy and the open air Shakespeare on Brownsea Island were great fun. We filled ourselves well at the Cream Tea and the Barbeque. These events couldn't happen without those who organised them so I would like to thank them on your behalf.

We held a coffee morning at Milborne Port and members from that area of Dorset were able to get to know each other. Many people bought plants from the plant stall so will remember that day as they watch them grow. I managed to get 1 cucumber to grow!

We are busy now planning events for the next few months. Do try to come to some of these, with friends and families. If you have transport problems, let me know and we can probably make arrangements for you.

I wrote to you recently with some details about a research project. If you would be willing to take part and have not yet sent the form to me please do so now. The researchers are willing to come down to Dorset to talk with us if we feel it is necessary. As

you can see it only requires a blood test and completion of a questionnaire. If by chance you haven't received my letter do phone for a copy.

I also sent details to you about a boat trip from Poole to visit Wareham. I need to know numbers very soon and the fish 'n chip orders have to be sent several days in advance.

October is our Lupus awareness month. It would be nice for members to hold a small coffee morning in their home. It's a wonderful way to get to know others who live in your part of the county. You could invite friends or neighbours so more people can hear about lupus. Please ring me or Debbie if you feel that you could do this.

Enjoy reading the newsletter.  
Bye for now

Margaret Hosking



### Contacts

In the panel on the left of this page you will find a list of Contacts for our group. These 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 a chat may help you. There is no need to sit at home and worry. Just pick up the phone.

Also, if you know of any members who are hospitalised or particularly unwell, please let one of the contacts or one of the other committee members.

## Members News

### Thinking of you.

Following on from my last newsletter may I say that it has been good to see Jan at some of our recent meetings! Hopefully all this treatment will help in the long run. Barbara, I am also glad to hear that you are out of hospital and slowly recovering. If anyone is in the neighbourhood of Bransgore, I am sure Barbara would welcome a visit.

I would also like to mention Sarah Williams, who is one of our contacts. She has been going through a particularly hard time recently. If anyone could visit her in Gillingham, I am sure she would love the company. Our thoughts are with you Sarah – I hope that it is not too long before your health improves.

To Denise, a quick mention. Glad to hear the operation on your thumb went well. Let's hope it will be much improved in the future.

### New members

Welcome to Mrs Barwick and Ms Kingsley, our 2 new members who joined during the summer months. If you would like to know a bit more about our group, or the events coming up, or may even wish to help at any of the events please call me anytime as I am in most evenings. Friends and family are always welcome at our get-togethers – in fact the more the merrier!



### Sunday 18<sup>th</sup> June COFFEE MORNING at Milborne Port, near Sherborne

Many thanks to Janet Heath, who organised our Coffee Morning at Church House, Milborne Port. The sun was shining brightly which made the trip to the north of the county even more pleasurable.

The hall was a good size and was cool, a welcome respite from the heat outside. Of the 20 people who attended, 8 were from the locality and as names and addresses were exchanged between them, I can only assume that they didn't know one another before.

We had the usual raffle as well as some of my many "spare" plants from the garden on sale. In addition I had managed to obtain some of the "Lupus" charity bracelets and sold most of them at this meeting. Having obtained a second consignment, I now have some more should anyone want any. They are only £1 each, come in 2 sizes and are a great conversation opener!!

Anyway I believe everyone enjoyed chatting to one another, which is the main purpose of our meetings. In addition £75.52 was collected and added to group funds. Thank you to everyone who attended. We would like to make this a regular fixture – **would anyone be interested?**

We are also looking into having a Group Sunday Christmas Lunch in the north of the county as well as in the east, as we did last year. **Would anyone be interested?**



### Saturday 2<sup>nd</sup> July Jazz & Swing open air concert, followed by fireworks, at Kingston Lacy, Wimborne.

A "swinging" time was had by all. In the end 7 of our members attended and I believe they all enjoyed it very much. The accessibility was good and the fireworks were fantastic!



### Sunday 10<sup>th</sup> July ANNUAL CREAM TEA. Janet & Chas' garden was immaculate and I would like to thank them both for all their hard work. The tables were beautifully laid and were the ideal setting for the Cream Tea (I think you may be hosting this now for the next few years.....).

Janet had been busy in the kitchen. The scones and cakes were delightful. In fact, my only criticism would be that there was just too much for my poor little stomach to manage! Anyway, the chocolate cake we bought in the auction afterwards was delicious and was lovely with my cup of tea later that evening. All the other feedback I got from everyone else was equally complimentary – so well done Janet, and thanks to Chas for all his help.

We raised a total of £114.30, which included the funds raised from the "Summer Flower" Quiz, which was won by Rhona. How come she is soooooo competitive? Well done Rhona – enjoy your vouchers.

## Previous events



**Browsea Open Air Theatre presents "Measure for Measure" on Browsea Island.**

In the end we managed to book for the Wednesday 27<sup>th</sup> performance, which was their opening night. Due to heavy rain, it was called off for that night. We made it the following night and all who attended thoroughly enjoyed the performance.



**Sunday 7<sup>th</sup> August ANNUAL BARBEQUE.**

Well, the sun shone, which was a much better start than we had had last year, when I had to work out how to seat over 30 people in the house! Luckily Plan 'B' was not required.

This year was a different matter, with the sun shining from early in the morning I could concentrate on the outdoor plan only. Thank heavens for our 2 huge silver birch trees which made a useful shade from the sun's rays.

I would personally like to thank all those of you who wrote to me afterwards to say how much you enjoyed yourselves at the Barbeque. Since I started to work full time I have not had so much time on my hands so it was good to see the day go off so well, without my having to do too much preparation. It's nice to know it was appreciated, and that all of you enjoyed yourselves. I would also like to thank all those willing helpers on the day.

Overall, including the money from the Raffle, we managed to raise £110.39. Thanks to everyone for coming along.

**Future Events**

**If anyone would like to attend any of these events but would have problems getting there, please phone Debbie on 01202 877390 as we may be able to get another member to collect you.**



**Saturday 10<sup>th</sup> September 11.30 (Boat sails at 12.00) - 3.30 BOAT TRIP inland from Poole Quay to Wareham for a 'Fish & Chip' lunch**

I am not sure whether this will have happened by the time I get this Newsletter out, but hopefully you should have received a mail shot from Margaret advising you of the details about this event. We had problems booking early as apparently all times are based on the tides.

We thought this would be nice once the tourists and children had returned to school before the cold weather sets in. We will meet up at Poole Quay to catch the boat, for a 3.5 hour trip along the inland waterways to Wareham, to have a fish & chip supper there, and then return back to Poole.

**REMEMBER OCTOBER IS LUPUS AWARENESS MONTH AND WE SHOULD TRY TO DO WHATEVER WE CAN TO RAISE PUBLIC AWARENESS. I HAVE MANY LEAFLETS IF YOU HAVE SOMEWHERE TO DISPLAY THEM – JUST GIVE ME A CALL.**



**Sunday 16<sup>th</sup> October "Go That Extra Mile"**

**SPONSORED WALK** in aid of **Lupus**. Last year you may recall that a few of us went on a sponsored walk, through the rain and many puddles to raise a considerable amount for Lupus. This year we thought it would be nice to walk along the seafront between Boscombe Pier and along to Bournemouth. We could arrange to be picked up so that the distance walked will not be too great and then off for a nice meal. The idea of the walk is not only to raise funds, but also to **raise awareness about our illness**. The seafront is a very popular place to walk and is nice and flat so that everyone, whether walking with sticks or wheelchairs or pushchairs may be able to join in. It would be really nice to have a cross-section of our membership involved so that we can show that lupus affects everyone.

I have not set a time as I would be happy to fit in the majority of walkers. If those of you who may travel to Bournemouth would like it in the afternoon (or perhaps you just don't feel good in the mornings) – let me know as it would be better to have more participants. It might be nice to take a stroll after lunch and then go for a cup of tea somewhere!

Do not worry if you do not want to be sponsored, the more that come along, the better.

If anyone is unable to come but would be able to get some sponsorship (including themselves) we would welcome any additional sponsorship – just call me and I will send you a list. If we get people's full addresses and postcodes with their signature on the list, then the charity will also receive gift aid from the Government, helping to boost funds still further! The latest News & Views mentions this in more detail.

I would be grateful if anyone who is interested in getting involved could contact me as soon as possible so that I can get the sponsorship forms and free T shirts. Many thanks.

As October is **Lupus Awareness Month** let's try and make a splash in Dorset!



**Saturday 22<sup>nd</sup> October**  
**COFFEE MORNING at the Howard Centre, Christchurch Hospital 10.30 - 12.00.**

As well as having a chance to have a chat and catch up on the news, we are planning to incorporate **card making** again into this meeting as the last one was such a success (and Christmas is on the way so cards are always useful). There is disabled access and plenty of parking at the Centre. Please feel free to bring along friends and family.

There is no charge for the card etc so come along and have a good time.



**Wednesday 26<sup>th</sup>**  
**October AWARENESS INFORMATION DESK & FUND RAISER outside ASDA, Bournemouth**

ASDA have a "health" area in the lobby, as you enter the Bournemouth store, and they have offered us a chance to man an Information Stand about Lupus there (during Lupus Awareness Month). We also thought that we would offer to pay someone's shopping bill that day if they pay £1 into raffle. This has been done by other charities in the past, and they have all done well out of it.

We are looking for volunteers, for maybe only an hour or so each to man the stall with several others for most of the day. Hopefully it would raise awareness and add to Group's funds. Is anyone interested – it should be a lot of fun?



**Sunday 20<sup>th</sup> November SKITTLES EVENING 7.00-10.30.** at Hamworthy Sports Club, Magna Road. Last year this event went so well that we thought that we would book it again.

I am sorry that some of you are unable to attend as it is an evening event but if you would've attended during the daytime perhaps you could let me know so that we could try an afternoon event next time.

This is so easy to do – it requires **NO** skill, as I can personally guarantee and is lots of fun. The venue has good disabled access and, as Barbara can confirm, bowling is still possible from a wheelchair. I am afraid the favourite is Rhona again (see comments re Summer Flower Quiz) as I am sure she practices regularly....Perhaps she needs a handicap – perhaps I shall make it doubles with me as her partner!

Anyway numbers are needed as **soon as possible**. We are proposing a charge of £5 per person, whether bowling or not, plus the cost of your bar meal. They like the order and money in advance so for those who are coming, I shall send out the menu and prices once I know how many are interested. We also thought it would be nice to have a "themed raffle". The theme is to be **Christmas**.



**Yes Santa will be here again! CHRISTMAS LUNCH to be held at The Sandbanks Hotel, Poole this time. We thought the view over the sea would be lovely. This will be held on Sunday 4<sup>th</sup> December.**

We have been lucky enough to get a reservation at the Sandbanks Hotel for our Christmas Lunch and have been guaranteed tables with a sea view! There is a choice of Starter/Main Course/Dessert and coffee, costing £19.50 per head, or 2 courses with coffee for £16.00.

I have enclosed a menu and would be grateful if you could indicate your preference and return it to me with a deposit of £5 per head **BEFORE** our Coffee Morning on 22<sup>nd</sup> October. All cheques should be made payable to "D Steel" and posted to my address on the front of this Newsletter. The balance will then be needed by 18<sup>th</sup> November. You are welcome to bring along friends or family.

If travelling is a problem, let me know. Many of us will be driving and I am sure we will be able to sort out transport. **Please let me know as soon as possible if you are coming as we may be limited for numbers. (I have already booked for 25 but they may not be able to accommodate late additions.)**



**CHRISTMAS FUN RUN in Burton, Christchurch on Sunday 11<sup>th</sup> December starting at 11.00a.m.**

No, I am not asking you to take part in a run!!!!!! We have been offered a donation if we can supply some marshals at

checkpoints, and an Information Stand at the Race start (and finish).

3 of us did this for the Dorset Lions earlier this year and we had great fun. In fact the amount donated is likely to be in the region of £2,000. There has been a delay in obtaining a more precise figure as it is taking some time to set up the necessary trust to control the saving and spending of the funds. These will be for the benefit of Dorset residents who suffer with Lupus.

The Information Stand previously was indoors so the cold weather didn't even matter. There was a great atmosphere and it amazed me how many people came up to talk to us on the stand. Most had never heard of Lupus. There were even some who approached us who had friends or family with the illness - one guy even had a sister with it and had no idea what was involved!

So any volunteers would be extremely welcome. P.S. I am still counting on Yvonne & Guy who volunteered for this event months ago!

### Future Events (in the pipeline)

- More Coffee mornings/afternoons in the North, West and East of the county
- An Easter or possibly Mothering Sunday Lunch

### LUPUS AWARENESS MONTH - OCTOBER

As you no doubt are aware, next month will be **Lupus Awareness Month**. We are trying to raise awareness and, as a group, our Sponsored Walk is part of this. In addition we were wondering if

some of you could host a "Coffee Meeting" in your area with some of your friends and family or even some of your local sufferers coming along.

Following our meeting in Milborne Port, earlier this quarter, several of you suggested that it would be nice if a few of you could see one another more often to help with the ups and downs of having and dealing with a chronic illness.

If you would be interested in doing something like this, please contact either Margaret or myself as we would be more than happy to help, if we can, and could contact others in your area if this would be a help.

### CHARITY BRACELETS

As mentioned before, I still have some Charity Bracelets (i.e. those rubber ones) which are purple and say:

#### "LUPUS? WHAT'S THAT?"

If anyone would like any they are £1 each. So give me a call on **01202 877390** if you are interested.

### CHILDREN

I am conscious that some of you have children and was wondering whether you would like some sort of event that could be held to include them? We have such a wide range of members and it would be nice to include **all** our members and their families. What could we do? Please phone me on **01202 877390** if you have any ideas, or if you want to tell me that you have a family and would like to be included on any "youngsters event"!

### TRAVEL INSURANCE

Has anyone had problems getting Travel Insurance? After one of our members had to cancel their holiday due to a flare, only to find they were not covered by their insurance several of us have made more effort to see whether our previous/existing policies truly covered our condition. When we looked into it, it would appear that many companies are not assessing the true risk and therefore refusing to pay up when needed. In that case, what is the point of paying any premium at all?

I eventually got my annual insurance through a company who used another company to underwrite my medical condition. They knew about lupus and, although they asked many detailed questions, I felt that any resulting policy would provide full protection. The second company told me I needed to pay an additional £20 over the cost of the standard policy. I then called the first company again and took out their policy.

I now feel confident that I have adequate protection should I need to make a claim in the next 12 months. I shall update you should the need arise. If anyone is interested, please call me for more details.

### EXPERT PATIENTS PLAN

In the February 2005 Newsletter I included an article about the **EXPERTS PATIENTS PLAN**. This is where the NHS runs a 6 week course to help people cope with any long term health condition, including lupus. I was surprised and disappointed to hear that when one of our members tried to book one of these courses, they were told that they had been cancelled

due to lack of interest. Would anyone else be interested in this type of course?

I went through a similar type of course with Christchurch Hospital in the last year or two and found that, although I had had rheumatoid arthritis for over 15 years at the time, the section on drug management and pain management was extremely useful for me. Others there had only recently been diagnosed with their illnesses and it helped them to just talk to someone who had longer term experiences in dealing with ill health.

In conclusion, it didn't matter how long you had been ill, there was always something of benefit to learn.

If you are interested call the Health Information Shop on 01202 318954 (or myself in case I could coordinate others in the group to get sufficient for one course.

### LLOYDSPHARMACY CAMPAIGN

Who has read their **News & Views**?

There is an article which mentions that Lloydspharmacies have a Charitable Fund collection box in each branch and that the charity for that fund is changed every 3 months. Charities, such as Diabetes UK, received £25,000 from their 3 months.

We are being asked to go into our local Lloydspharmacy and pick up a leaflet to nominate Lupus UK to become one of the Charitable Fund's Chosen Charities.

### WHAT DO YOU WANT?

Any suggestions re what you would like in this newsletter? Are there any issues you would like raised? What experiences have you had with regard to your medical treatment? I would welcome any suggestions or letters to put in the Newsletter.

Following on from that, what would you like in your **Dorset Lupus** website?

Please phone, email or write to me. All suggestions will be gratefully received.



### Website and E mail facility

**WHO HAS VISITED OUR WEBSITE?**

[www.dorsetlupus.com](http://www.dorsetlupus.com)

The Newsletters and Upcoming events are listed so no excuses for forgetting our meetings!

**Registration Update** Another member has been added to my list since last time. When registering could you please let me know whether your computer accepts Word as I have to do something different to it to make the newsletter legible for you (I think!).

### LIBRARY

Don't forget our library is free of charge to all members. If you would like to borrow any of the books please contact either of our librarians, Guy & Yvonne Hosking, on 01202 575924 for any books on Lupus.

Alternatively if you have read a book which you think someone

else would find useful relating to Lupus or any linked illnesses, please let them know so that we can increase our stock for the library.

### CHRISTMAS CARDS AND LUPUS MERCHANDISE

As you will have read from your latest News & Views, the new Lupus Merchandise catalogue will be coming out shortly. Last year we ordered a lot of merchandise, and Christmas Cards, which were popular at our meetings. If there is anything you wish to order please let me know as I can do a block order. It only takes a few days, and you will avoid having to pay any postage. The cards last year were of an excellent quality and I had to order and reorder.....so let me know if there is anything you want.

### FEATURE ARTICLE

Please find attached an article, given to me, praising the benefits of Green Tea with Autoimmune Diseases including Chronic Fatigue and Fibromyalgia Related illness. Let me know how you get on.

I apologise if the Article is not enclosed as someone at the Committee meeting has picked it up with their paperwork. I shall do my best to recover it before these letters get posted out!

### Used Postage Stamps

I received lots of stamps from Poole hospital via one of our

members who works there.  
Thank you.

I have also received a lot of stamps from my new employment (as well as some from my old employer). In fact I have now sent just under 3,000 stamps from us in the past few months. Well done and keep them coming.

Don't forget 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.

Thank you

### S.O.S.

Following Jenny's ill health, we are looking for someone to take over the position of Secretary. We have 3 committee meetings a year and the secretary would be needed to write up/type up the minutes. Margaret would also like someone to send out cards to those members who are not well and just have someone to help with all the paperwork that comes through from Head Office. As I now work full time I am unable to help with some of these extra jobs.

If anyone is interested please call Margaret.

### AND FINALLY

Finally I would like to thank BAE Systems at Christchurch once again for printing this newsletter

for us free of charge. It is very much appreciated. As a small local charity we need all the help we can get from local businesses.

*Debbie Steel*

Well here are the dates for your Notice Board to cut out and keep. This lot should keep you busy for a while.



### Dates For Your

### Diary



Sat 10<sup>th</sup> Sept 11.30-3.30  
– Boat Trip with Fish & Chips, from Poole Quay to Wareham and back again.

Sun 16<sup>th</sup> Oct  
– Sponsored Walk from Boscombe Pier for "Go That Extra Mile" campaign

Sat 22<sup>nd</sup> Oct 10.30-12.00  
– Coffee Morning and Card Workshop at Howard Centre, Christchurch Hospital

Wed 26<sup>th</sup> Oct  
ASDA, Bournemouth with Information Stand and fund raising

Sun 27<sup>th</sup> Nov 7.00-10.30  
- Skittles Evening at Hamworthy Sports Club, Magna Road

Sun 4<sup>th</sup> Dec 12.00-2.00  
– Christmas Meal at Sandbanks Hotel, Poole

Sun 11<sup>th</sup> Dec 11.00-1.00  
– Fun Run in Burton, Christchurch to raise funds and promote awareness