



# DORSET LUPUS GROUP NEWSLETTER

## Winter

WINTER EDITION 2014

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OUR PAGE AND GET INVOLVED!**

### COMMITTEE MEMBERS

**Chairperson:** Debbie Steel

01202 877390  
[debbie.steel@dorsetlupus.com](mailto:debbie.steel@dorsetlupus.com)

**Vice-Chair & Newsletter  
Editor:** Tamsin Campbellton  
01202 041149  
[tamsin@dorsetlupus.com](mailto:tamsin@dorsetlupus.com)

**Secretary & Treasurer:**  
David Mays  
[d.mays@dorsetlupus.com](mailto:d.mays@dorsetlupus.com)

**Publicity & Events:  
East Dorset:** Ann Mays  
[d.mays@dorsetlupus.com](mailto:d.mays@dorsetlupus.com)

**West Dorset:** Rose Smeeton  
01305 761454  
[rosemary.smeeton2@btinternet.com](mailto:rosemary.smeeton2@btinternet.com)

**Website:** Debbie

**Members:**  
Mrs Janet Bourne  
01202 874303  
[janetbourne1@talktalk.net](mailto:janetbourne1@talktalk.net)  
Shirley Merrett  
[spmerrett@ntlworld.com](mailto:spmerrett@ntlworld.com)

**Raffle:** Mrs Carol Berkhauser  
01202 303557 [carol.berkhauer@hotmail.com](mailto:carol.berkhauer@hotmail.com)

**Benefits Advice:**  
Jean Durrant 01258 860565  
**Cards:** Smiley

**Contacts:**  
**Tamsin C** 01202 041149  
**Jean Durrant** 01258 860565  
**Debbie Steel** 01202 877390  
**Rose Smeeton** 01305761454

### PATRONS

Christopher Chope OBE MP  
and Christo Chope & Dr. Neil  
Hopkinson DM FRCP

### SPONSORS

If you would like to sponsor  
us or know a company who  
would, please get in touch.



## Merry Christmas ...

Hello everyone and welcome to our Winter Newsletter.

We have organised some great events over the coming months and hope that many of you will come along to see us and join in. It's always such a busy time of the year!

We have had an eventful year with the arrival of our Lupus Nurse, Carol Brumpton, in April and the introduction of regular "Drop In" Coffee Mornings/ Afternoons in the west, east and north of the county. Our range of Information Stands worked well during Lupus Awareness Month (October), as we met several people who had been recently diagnosed and wanted to find out more about lupus. It always amazes me that no matter how many times you may stand in a major hospital, there are always staff members that come up and ask "What is Lupus?!" Just goes to show how important it is to spread awareness to everyone. If we only help one person in the whole month, it has all been worth it.

However, on a more sombre note, I feel it is important to share with you in this Newsletter the changes that will be occurring at the next A.G.M. in April so that you will have time to think and consider whether you may

be able to help run the Group.

Both Tamsin and I, having been on the committee for a number of years in various roles, will be standing down in April. David & Ann Mays have recently moved to Romsey and, whilst they are currently continuing with their roles on the Committee, they need time to settle into their new home near their family and will be standing down in April as well. As you may recall I mentioned that Janet Bourne had been seriously ill and has spent many weeks in a London hospital. I can report that she is now home and recovering well, but her improvement is slow and she too cannot continue on the Committee for the foreseeable future. As a result we shall be losing our Chair, Vice Chair, Treasurer and Secretary as well as those who help organise and run the Group.

On the positive side Rose is happy to remain on the Committee and continue developing the Contact network in the west of the county, as well as remaining a Lupus UK Contact. Sarah's meetings in Sherborne are also progressing well and serve as a point of contact for those living in the north of the County. Tamsin is happy to continue producing the Newsletter and acting as a Contact for our area too.

Carol Brumpton, our Lupus Nurse, is keen to help us wherever she can as the specialist group of lupus clinicians grows at Christchurch Hospital.

So, if you are able to offer any help, and are willing to take on any of the roles that form a Committee, then please contact either Tamsin or myself before the A.G.M.

On that final note may I wish you all a very Merry Christmas and all the very best for the New Year.

**Debbie x**

## Happy New Year ...

Hello all.

I cannot believe how fast this year has gone and now once again we are hitting the cold wet and windy winter weather. If anyone suffers from Raynaud's there is a great piece from Dr Hopkinson about it on page 5, along with an interesting article about probiotics and lupus on page 4.

Sadly to say a number of our committee members will be standing down in April next year and so there are several positions available. If you might be interested in taking a more active part in your group and would like to know a bit more please give myself or Debbie a call.

Finally I wish you all a very Merry Christmas and Happy New Year.

**Tamsin x**

## A Review of Past Events...

### AWARENESS STANDS THROUGHOUT OCTOBER

Worthwhile information stands held at each of the hospitals in Dorset. Unfortunately we had to cancel the Christchurch Hospital stand on 1st October due to lack of volunteers available.

### COFFEE & CHAT WITH SPEAKER NOV 15TH

Well attended session and interesting talks on the update from our Lupus Nurse based at Christchurch Hospital Clinic and Charlie Monkcom speaking on 'My Health My Way' - an NHS initiative for health coaches to provide non clinical personal support to help you get to grips with your health and well being. See page 3 for synopsis.



*Photos of Coffee & Chat Nov 15th;  
L: Lupus Nurse Carol Brumpton  
R: Speaker Charlie Monkcom*

## South & West Coffee & Chats

The coffee and chats in the South & West will restart in the New Year on any day of the week if there is enough interest from members.

Please contact Rose Smeeton on 01305 761454 or email:

[rosemary.smeeton2@btinternet.com](mailto:rosemary.smeeton2@btinternet.com)



## Future Events...



### **CHRISTMAS COFFEE & CHAT ON SAT 6TH DEC AT 10AM; LEIGH PARK COMMUNITY CENTRE, GORDON ROAD, WIMBORNE MINSTER, DORSET, BH21 2AR**

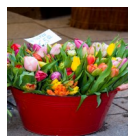
Please come join us and celebrate our last coffee and chat of 2014. The community centre is next door to Wimborne Rugby Club. We will provide drinks and nibbles (no charge). 10am - 12pm. There will be all the usual Lupus goodies on sale along with a Christmas raffle and ample free parking is available. Hope to see you there!



### **NEW YEARS SUPPER ON SUN JAN 25TH 2015 AT 5PM; THE KINGS ARMS, 77 RINGWOOD ROAD, LONGHAM BOURNEMOUTH BH22 9AA**

There are only a limited amount of spaces for this event so please let Debbie know asap if you would like to have a scrumptious dinner out with us. The menu is shown on Page

6, the cost is £25 per head including 3 courses and gratuity (excluding drinks). When you book your place with Debbie please let her know your menu choices along with a £10 deposit per person (cheque to Dorset Lupus Group or bring cash to the coffee morning on 6th Dec.). Looking forward to seeing old faces and new.



### **FUNDRAISING AT MANOR FARM, HAMPRESTON, WIMBORNE, BH21 7LX SAT 28TH FEB & SUN 1ST MARCH 2015; 12-3PM; MAY 31ST 1-4; AUG 1ST 1-5; AUG 5TH 2-5**

Anne & Guy Trehane once again hosting, require help with serving refreshments when they open their garden to the Public under the "NGS Yellow Book" Scheme. As well as having great fun, we also manage to raise a considerable amount for lupus research. We always need helpers so if you can spare some time to serve teas, or if you are able to make some homemade soup for the two days in February - please give Debbie a call.

### **COFFEE & CHAT WITH THAI CHI TALK & DEMO ON SAT 7TH FEB 2015 AT 10AM-12PM VENUE TBC WILL BE IN DORCHESTER AREA**

Come along and join us for a coffee and chat morning along with a Thai Chi talk and demonstration session with Sue Branch

[www.suebranch.co.uk](http://www.suebranch.co.uk), it is an extremely therapeutic and gentle form of exercise and good for those suffering with lupus, as well as being great fun. Please watch out for details on the venue which will be emailed out and on our website!

### **AGM ON 11TH APRIL 2015 AT HOLIDAY INN EXPRESS, POOLE; 10AM - 12PM**

It's that time of year again and we will be holding our annual AGM at the Holiday Inn Express in Poole (same venue as last year). Parking is £3 if you go to reception to get your ticket. Refreshments will be provided. Chris Maker from Lupus UK will be giving a talk along with our Patron Dr Neil Hopkinson.

## Sarah's Stall ...

In early October one of our members, Sarah Dunstan with the help of her friends and family, held a Bake Stand and Information Day at Sherborne. For those who missed the write up in the Stour and Avon and Blackmore Vale publications here it is!

In October Sarah Dunstan, together with her friends and family, organised a sale of cakes, jewellery and other craft items, in Sherborne to raise money to help with the treatment of Lupus, an incurable disease affecting the immune system where over 90% of sufferers are women. They managed to raise over £450 for her cause, a wonderful achievement especially as Sarah herself suffers with this illness where extreme fatigue is just one of the many symptoms. On Saturday the local support group, Dorset Lupus Group, held a Coffee Morning to present the Pulse Oximeters to Carol Brumpton who was representing the local Bournemouth & Christchurch NHS Trust. Carol is the Lupus Nurse, recently appointed to support the growing team of specialist doctors, based at Christchurch Hospital, to treat patients with lupus in the county.



Well done Sarah. (L to R Sarah Dunstan, Carol Brumpton Lupus Nurse, Debbie Steel

## Your Story?

If anyone would like to write in and tell us their Lupus story please email it to me on; [tamsin@dorsetlupus.com](mailto:tamsin@dorsetlupus.com) We would love to hear it - maybe its similar to someone else's!

## My Health My Way ...

At the coffee and chat morning in November we had a speaker from 'My Health My Way', Charlie Monkcom, - a free self management support service for people living in Dorset whose lives are affected with long term health conditions.

Based on the latest research and experience, Dorset CCG has commissioned a completely new service that focuses on enabling people with long-term health conditions to develop the confidence, knowledge and skills they need to manage the impact of their health condition on their day to day lives.

### WHO CAN ACCESS IT?

Anyone with a long term health condition or their carer and who is registered with a GP in Dorset or who lives in the county.

### HOW IS IT DELIVERED?

By fully trained self-management coaches supervised by an external clinical psychologist. They work with a mixture of approaches designed to meet individual needs including:

- one to one coaching
- Telephone support
- Group work
- Online tools
- Structured support groups

### HOW DO INDIVIDUALS ACCESS THE SERVICE?

People can access the service by telephoning 0303 303 0153, going to the website [www.myhealthdorset.org.uk](http://www.myhealthdorset.org.uk) or by emailing [info@myhealthdorset.org.uk](mailto:info@myhealthdorset.org.uk). We will then be in touch within two working days and if appropriate arrange an

appointment with one of the self-management coaches.

### HOW WILL THE INDIVIDUAL BENEFIT?

It can be difficult for people with health conditions to always feel in control of symptoms, manage changes to their lifestyle and digest all the information they are given by healthcare professionals.

With the type of support available from My Health My Way you can build your skills, knowledge and confidence to start taking control of your health condition, rather than let it control you.

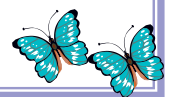
You will be supported to build and maintain your confidence to self-manage areas like pain or fatigue, exercise or dietary changes, anxiety or depression.

We will also work with you to help you make better, more informed choices about medications and improve your ability to converse with healthcare professionals about your care options.

## LUPUS UK 2015 Subscriptions

Your 2015 Lupus UK subscription will be due on 1st January so, if you do not pay by standing order, don't forget to send your money to them.

It is only £10 for a single membership or £15 for two people at the same address!



## AGM & Committee: April 11th 2015

*There will be vacancies for Chair; Vice-Chair; Treasurer; Secretary.*

If you are interested in any of these positions please give Debbie or Tamsin a call prior to the AGM to show your interest and for more information.

01202 877390 (Debbie) or 07816 069566 (Tamsin)



## Interesting Read: Study suggests altering gut bacteria may put Lupus into remission...

### Designs for Health Research & Education Blog

Posted on Tue, Nov 04, 2014

The connection between the gut and autoimmune disease is in the news once again. Just this past month (Sept. 2014) a journal article was published on the [changes in intestinal barrier function \(leaky gut\) with multiple sclerosis](#).

Researchers suggested that future drugs to treat MS should not only focus on the central nervous system, but also on the intestines by repairing and restoring the intestinal barrier. It's important to remember that the gastrointestinal tract is 80% of our immune system. Whenever inflammation is present, the tight junctions and intestinal mucosa can become damaged, causing gaps or "pores" in the lining of the GI tract. Then, toxic byproducts in the digestive tract can be absorbed into the bloodstream and transported to the liver. The molecules of food and toxins are "leaked" through the GI lining and eventually they affect systems throughout the body, causing joint inflammation, toxins expressed in skin disorders, autoimmune conditions and food sensitivities.

There has been a sharp increase in the incidence of autoimmune disorders over the past several decades. Why is this occurring? The answers may be found in the current medical research, but you would probably never know it by visiting a doctor. The above mentioned study is a perfect example between the big disconnect between medical research, which is often outstanding, and the practice of traditional medicine, which

often leaves quite a bit to be desired when it comes to the management of chronic disorders.

The typical allopathic clinical approach to autoimmune diseases focuses on the management of symptoms with various anti-inflammatory medications, chemotherapeutics, and also very potent immunosuppressive agents with serious potential side-effects like leukemia and lymphoma. These approaches certainly can provide substantial relief to the patient, but they do not really get to the cause of these conditions, and some research suggests that these approaches may result in a furthering of the pathological process.

Gut bacteria has been identified as an important environmental factor in overall health and autoimmune disease. A recent study demonstrated the role of the gut microbiota in lupus. According to research published in *Applied and Environmental Microbiology*, *Lactobacillus* species were shown to reduce the severity of lupus symptoms, while *Lachnospiraceae*, a type of Clostridia, correlated with a worsening of symptoms.

In this study, researchers presented that mouse models of lupus had higher levels of *Lachnospiraceae* and lower *Lactobacillus* than control mice. In addition, they compared male and female mice, and found that the differences were present only in females. These results suggest that the gut bacteria may contribute to lupus, a disease which is much more common in women. Also, the gut microbiota was monitored over time in both lupus and control mice. As a result, they found that Clostridia was increased

in both early and late stages of the disease.

In further experiments, the team treated the symptoms in the lupus mice with either retinoic acid alone or vitamin A with retinoic acid. The latter worsened the symptoms, which was surprising since it had been expected to reduce them. In these mice, Clostridia increased and *Lactobacillus* decreased. However, retinoic acid alone did improve the symptoms and the dysbiosis.

The research suggests that altering the gut microbiota could help lead to a remission of lupus. Thus, patients with lupus should consume *Lactobacillus* - containing probiotics to aid in reducing lupus exacerbations. The use of probiotics, prebiotics, and antimicrobials can improve the microbiota and reduce lupus symptoms.

The team was inspired to perform this research based upon a study where type 1 diabetes was found to be dependent on gut microbiota. Type 1 diabetes and lupus are different diseases, but all autoimmunity has the same common environmental triggers. It would be beneficial if every patient with autoimmune disorders underwent a comprehensive digestive stool analysis (in my opinion and which modern research supports). There are several other factors to consider that play a role in autoimmunity, such as gluten intolerance, food sensitivities, gastrointestinal infections, heavy metal toxicity and vitamin D deficiency.

by Michael Jurgelewicz,  
DC, DACBN, DCBCN



## Dr H's Spot ...



I hope that you have all enjoyed the very good weather that we have had this summer. Now that the temperature outside has got noticeably colder some of you may suffer from worsening attacks of Raynaud's. Maurice Raynaud was a French physician who first described the typical colour changes that can affect the hands and feet. During an attack that can be often triggered by a change in temperature, the fingers can turn white, and then blue, before becoming red and painful during rewarming. Not all the fingers may be affected and only a part of the finger may be involved, but the appearance is very characteristic when it does occur. There has been a lot of confusion about the terminology of Raynaud's (Phenomenon, syndrome, or disease?). I prefer to keep it simple and call it Primary Raynaud's when there is no underlying illness, and Secondary Raynaud's when Lupus is the main diagnosis (although other conditions can cause it as well!).

The appearance of the fingers can be quite dramatic during attack but the good news is that for the vast majority of patients it is a painful nuisance rather than a condition that causes serious complications. It is very rare indeed for

example for the blood flow to be cut off altogether.

It is important to adopt some simple measures: stopping smoking is always important, as is keeping warm. Wearing good quality thermal gloves when outside and also wearing a hat in cold weather (we can lose a lot of heat from the head on a cold day even with a good head of hair). Complimentary treatments may also help and some promote Ginkgo Biloba and others, fish oils and oil of Evening Primrose. When a prescription medication is required we tend to start with Nifedipine ('Adalat') which is still the only licensed drug in the UK for this condition. For the rare situation when digital ulcers occur we often use an intravenous preparation called iloprost. I emphasise that this would be most unusual in Lupus.

So, keep warm this winter when venturing out, wear gloves, and think about a hat!

I wish you all a very happy Christmas and New Year!

Dr H.

## New interactive sessions ...

### Help us plan our interactive education sessions ...

Two of our four key values at the Royal Bournemouth & Christchurch hospitals are 'Communicate' and 'Improve'.

As such, our Rheumatology Department at Christchurch Hospital would like to offer interactive patient education sessions in 2015 for patients with Lupus and Connective Tissue Diseases.

We would like the input of our patients to help choose which topics you would like us to cover for your benefit.

**Please contact Carol Brumpton, Lupus Nurse Specialist on 01202 705302 or email [Carol.Brumpton@rbch.nhs.uk](mailto:Carol.Brumpton@rbch.nhs.uk) with your top three topics you would like to be covered.**



## MediAlert Foundation...



MediAlert is the only non-profit registered charity providing a life-saving identification system for individuals with hidden medical conditions and allergies. This takes the form of body worn bracelets or necklets bearing the MediAlert symbol on the disc and supported by a 24hr emergency telephone service. Each member receives an emblem that is engraved with the wearers main medical condition(s) or vital details, a personal ID number and a 24 hour telephone number that can access their details from anywhere in the world in over 100 languages.

There is an annual fee of £25 for membership plus the cost of bracelet chosen starting from £19.95. Contact MediAlert on **0800 581420** email: [info@medicalert.org.uk](mailto:info@medicalert.org.uk) or see [www.medicalert.org.uk](http://www.medicalert.org.uk).

## Members Assistance Fund

The Dorset Lupus Group have a trust fund, with just over £1900 in it, and would like to be able to use this money to help our members. Donations have been from the Dorset Lions and from the Bourne Lodge, along with private donations with the stipulation that it was to be used for local sufferers of lupus only.

If anyone would like to speak to Tamsin confidentially, to see whether Dorset Lupus would be able to help, please call her on 01202 041149 or write to 4 Hurn Road, Christchurch, BH23 2RN Dorset.

Strict confidentiality will be followed at all times.



## NURSE-LED LUPUS CLINIC

Carol Brumpton will be holding a Nurse-led Lupus clinic EVERY Wednesday Morning AND EVERY OTHER Thursday Afternoon. Please contact Carol for more details on 01202 705302



## GIFT AID

Please remember that ANYTIME and EVERYTIME you make a donation it would help us if it was accompanied by a signed Gift Aid form from yourself IF you are a UK Tax payer and wish Lupus UK to claim gift aid on your behalf. It will not cost you anymore, and will boost your contribution to Lupus UK



## New Years Supper Menu Choices ...

**Venue: The Kings Arms Longham**

**Time: 5pm**

**Date: 25th January 2015**

\*\*\*

Honey roasted butternut squash and sweet potato soup

Prawn and crayfish tian bound in a seafood sauce served with granary bread

Pulled ham hock, confit chicken and garlic pressing, toasted brioche & homemade chutney

Kings Arms cheese soufflé served with mixed leaves dressed in a walnut dressing

\*\*\*\*\*

Roast Sirloin of beef served with Yorkshire pudding, roast potatoes, vegetables & red watercress  
(Supplement £2.00)

Roast loin of cider fed pork served with stuffing, roast potatoes, vegetables & crackling

Roast chicken on the bone served with stuffing, roast potatoes, vegetables & cranberry sauce

Goat's cheese, beetroot and chive risotto served with a side salad & garlic bread

\*\*\*\*\*

Autumn berry Kings Arms mess, chantilly cream, mixed berries & fresh meringue

Pear & blackberry crumble served with vanilla ice cream

Duo of cheese cakes, white chocolate & vanilla

Selection of ice creams & sorbets

Please make your menu choices and give your deposit at the time of booking - limited number of places available!

## Your Local Committee...

**Chair & Website:** Debbie Steel  
7 Ebor Close, West Parley,  
FERNDOWN, BH22 8LZ  
01202 877390 / 07709 308002  
[debbie.steel@dorsetlupus.com](mailto:debbie.steel@dorsetlupus.com)

**Vice Chair & Newsletter:**  
Tamsin Campbelton  
4 Hurn Road, CHRISTCHURCH,  
BH23 2RN  
01202 041149 / 07816 069566  
[tamsin@dorsetlupus.com](mailto:tamsin@dorsetlupus.com)

**Secretary & Treasurer:**  
David Mays  
[d.mays@dorsetlupus.com](mailto:d.mays@dorsetlupus.com)

**Publicity & Events:**  
**East Dorset:** Ann Mays  
[d.mays@dorsetlupus.com](mailto:d.mays@dorsetlupus.com)

**West Dorset:** Rose Smeeton  
01305 761454  
[rosemary.smeeton2@btinternet.com](mailto:rosemary.smeeton2@btinternet.com)

**Other Committee Members:**  
Mrs Janet Bourne  
01202 874303 / 07977 231304  
[janetbourne1@talktalk.net](mailto:janetbourne1@talktalk.net)

Shirley Merrett  
[spmerrett@ntlworld.com](mailto:spmerrett@ntlworld.com)

**Non Committee Members:**  
**Raffles:**  
Mrs Carol Berkhauser  
01202 303557 / 07798 804434  
[carol.berkhauer@hotmail.com](mailto:carol.berkhauer@hotmail.com)

**Greeting Cards:**  
Mrs Yvonne Bartlett  
01202 535123  
[smiley.face@sky.com](mailto:smiley.face@sky.com)

**Benefits Advice:**  
Jean Durrant  
01258 860565  
[jeandurrant@dorsetlupus.com](mailto:jeandurrant@dorsetlupus.com)

## Lupus UK wristbands

These wristbands are now available from the Lupus UK website to help spread awareness of Lupus featuring logo & website details - price £1.00. Debbie has a supply of these so anyone who would like to get one can save on postage costs by getting them from Debbie!



## USED 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 Debbie in an envelope.



## PLEA FOR HELP!

### Helpers needed for the Open Garden this year

Without help serving the teas and cakes/collecting trays/and washing up... it can't go ahead as the Trehanes rely on help from the DLG - only fair as we get the proceeds!

If you can lend a hand please call Debbie with your preference on days to help.

## Dates for your Diary...



**Sat Dec 6th**

Leigh Park Community Centre,  
Gordon Road, Wimborne  
Minster, Dorset, BH21 2AR

Xmas Coffee Morning 10am-12pm

\*\*

**Sun Jan 25th 2015**

New Year Supper at The Kings Arms, Longham 5pm

\*\*

**Sat 7th Feb 2015**

Coffee & Chat with Thai Chi Demo/ Talk Dorchester venue tbc 10-12pm

\*\*

**Sat 28th Feb & Sun 1st March 2015**

Open Gardens at Manor Farm Hampreston 12 - 3pm

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**Sat April 11th 2015**

AGM at Holiday Inn Express, Poole; 10am - 12pm

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**Sun 31st May 2015**

Open Gardens at Manor Farm Hampreston 1 - 4pm

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**Sat 1st Aug 2015**

Open Gardens at Manor Farm Hampreston 1 - 5pm

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**Wed 5th Aug 2015**

Open Gardens at Manor Farm Hampreston 2 - 5pm