



# DORSET LUPUS GROUP NEWSLETTER

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## Patrons

Dr Neil Hopkinson DM FRCP

Christopher Chope OBE MP &  
Christo Chope

*A word from your Coordinator...*

Welcome to this Spring edition of the Dorset Lupus Group Newsletter – It's hard to believe Spring is here, but seeing the flowers beginning to come up, brings us hope for better weather.



How are you? Has there been any changes in your GP surgery? We'd like to know if the NHS Transformation Project Plans for Dorset are affecting your area? Please keep us informed.

Some good news – The Hampreston Teas are well underway and have already raised £253 for just two afternoons in February. Please see further in the newsletter for future dates for this year.

Shirley Merrett and Rosemary Smeeton are hoping to re-establish talks to our local healthcare professionals, Head Office have equipped them with 20 copies of the Lupus and Diagnosis books to hand out.

What do you do with your old copy of 'News and Views'? Why not drop it off at your local GP practice – not only is it informative but it also is a simple way of raising awareness of Lupus.

I wish you all a super Spring and Summer and look forward to seeing you at an event. We are off to New York City in September and I'm hoping to meet up with the NYC local lupus group.... I may have some news to report in the Autumn. Remember I am always here to help in any way I can. Keep well.

Helen xx

## Report from National Council Meeting - Helen Bifield

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This was my third National Council meeting in London, held at the Grange City Hotel on March 11th.

There were 19 members at the meeting which consisted of CEO Chris Maker and Paul Howard from Head Office, Kevin Weston Chairman, Tina Stemp Treasurer, David Hopkins Secretary, Yvonne Norton and Jan Roberts Trustees, Liz Vale Co-Opted trustee and representatives from Devon and Cornwall, Hampshire, East, West and South London, South and East Scotland, East Midlands, Strathclyde, West Midlands, North Wales and us Dorset 😊 .

It was a good day with a lot discussed, some discouraging reports of lack of attendance at events were noted from several Counties but from most there is a lot of positive work, support and fundraising being done by Lupus members and their families across Britain.

There are to be changes in the way the board of trustees are formed – currently the board is made up of 8 Lupus members and group chair persons with 1 co-opted person. From May 6<sup>th</sup> 2017 at the AGM in Winchester, a new plan will be adopted - there will be a maximum of 8 Lupus members with an additional 2 further trustees with specialist skills (these could be Consultants, GP, medical professionals etc) these 10 people will serve for a 3 year period. In addition there will be 2 Co-opted trustees for ‘specific purposes’ who will serve for a 1 year period. The idea is to open up the trustee committee to better deal with all aspects of Lupus UK.

Head Office confirmed they have agreed a grant of £246k for a Specialist Lupus Nurse Band 6 (5 year period) at Queen Elizabeth Hospital, Birmingham.

Yvonne Norton is looking to stand down from representing Lupus UK at Lupus Europe.

The day finished with thanks from the trustees to all coordinators and chairs for their hard work.

## NGS Manor Farm at Hampreston

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### NGS Manor Farm Teas Fundraiser, Hampreston

Lupus Group members serve the teas and cakes and the funds from the refreshments go to the work of Lupus UK.

If you would like to help, please contact Debbie Steel 01202 877390

**Sunday 11 June 1-5pm**

**Sunday 30 July 1-5pm**

**Wednesday 3 August 1-5pm**

**Sunday 13 August 1-5pm**



## **‘Boutique In a Bus’ Fundraiser - Saturday 27th May 2-4.30pm**

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Chris McKenna has organised this fundraiser in Puddletown, Dorchester.

The bus is filled with lot's of lovely clothes, bags and accessories for women. All items on the bus are priced under £50.

**There will be Tea/Coffee and cakes on the day & a raffle. All are Welcome.**

The bus will be at: **2 Kindle Cottage, The Old Coalyard, Styles Lane, Puddletown, Nr Dorchester, DT2 8SJ**



## Do's & Don'ts of Living with Sjögren's and Raynaud's

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Two overlapping conditions known to many with Lupus are Sjögren's syndrome and Raynaud's disease, also known as Raynauds phenomenon. Here are some of the practical do's and don'ts to living with these diseases.

**Sjögren's** syndrome affects the body's ability to produce moisture in the glands of the eyes, nose, mouth and vagina. Although the hallmark symptoms are dry eyes and mouth. Sjögren's may also cause dysfunction of other organs such as the kidneys, gastrointestinal system, blood vessels, lungs, liver, pancreas and the central nervous system. Patients may also experience extreme fatigue and joint pain and have a higher risk of developing lymphoma. Sjögren's syndrome is classified as primary when it occurs alone, or secondary when another connective tissue disease is present. Prescription medicines for dry eyes and mouth are available, as are various over the counter lubricating products.

- Do keep high humidity work and home environments
- Do breathe through your nose not your mouth
- Do be aware that many prescribed medications cause dry mouth (xerostomia)
- Do pay close attention to the health of your teeth and gums
- Don't consume spicy foods or acidic juices, fruits or vegetables which can irritate mouth tissue
- Don't eat hard crunchy foods that can irritate or tear mouth tissue
- Don't smoke or spend time in locations where others are smoking
- Don't use tartar-control toothpaste or teeth whitening products, which can irritate mouth tissue
- Don't overuse alcohol (including wine) or mouthwashes that contain alcohol, as these can dry the mouth further

**Raynauds's** disease causes narrowing of the blood vessels, which most commonly affects the fingers and toes. When blood can't get to the surface of the skin, the affected areas turn white and blue. When the blood flow returns, the skin turns red and throbs or tingles. In severe cases, loss of blood flow can cause sores or tissue death. Prescription medicines can help keep the blood vessels open, but the best treatment is to avoid the cause of the attacks.

- Do avoid abrupt changes in temperature, especially going from warm air to air conditioning
- Do soak your hands or feet in warm water at the first signs of an attack
- Do use mittens when taking anything out of the freezer

- Do avoid excess stress
- Do see your doctor if your symptoms become worse or if you notice any sores on your fingers or toes
- Don't smoke or spend time in locations where others are smoking
- Don't use vibrating tools, such as an electric hand mixer or power tools
- Don't go outside in cold weather without a coat, hat, warm socks and mittens (not gloves which allow more cold air to get between the fingers)

Source: Lupus Foundation of America Lupus Now Magazine ([www.lupus.org](http://www.lupus.org))

## Lupus Events in Hampshire

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# Hampshire Lupus Information Day

**Saturday 6 May 1:30pm**

**At The Guildhall Winchester SO23 9GH**

**Talks by**

**Professor Chris Edwards Consultant in Rheumatology – Southampton**

**Dr Neil Buchanan, Consultant in Rheumatology – Royal County Hospital,  
Winchester**

**Colin Beaver – Matron for Rheumatology, Portsmouth**

**Carol Brumpton, Lupus Nurse Specialist – Christchurch Hospital**

**For further details and to book a free ticket email :  
[info@lupusuk.org.uk](mailto:info@lupusuk.org.uk) or phone Paul Howard on 01708 731251**

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**It would be lovely if we could support Carol our Specialist Nurse from  
Christchurch by attending this event.**

## Update from the team at Christchurch Rheumatology

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We are delighted to report that the improvements to the Christchurch Hospital site are continuing at pace, with the lovely new reception area opening any day. While there will still be some ongoing improvements to come, the out-patient refurbishment is now complete, with a brand new X-ray Department and redeveloped waiting area.

These developments and changes reflect the ongoing commitment of the Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust to work in partnership with patients and invest in the future of healthcare in Dorset.

Undoubtedly, local NHS services will continue to go through a period of change as services are redesigned to meet the needs of the local population. However, our focus is our absolute commitment to delivering high quality care for our patients and we are always keen to hear our patients' views and work closely with them to make service improvements.

Although we look after adult patients with Lupus of all ages and genders, I thought I would take the opportunity to discuss the latest European guidelines for women's health published by the European League Against Rheumatism (EULAR) in March 2017 and, in particular, how they relate to pregnancy planning.

These new guidelines are comprehensive and have been developed using an evidence based approach.

At Christchurch we place great emphasis on discussing family planning and ensuring our patients have access to information prior to conception. This emphasis on high quality care continues throughout pregnancy and after delivery.

Encouragingly, the guidelines say that most women can have successful pregnancies, but encourages clinicians to promote the health of mum and baby. Concerns centre on the potential impact of any pregnancy on maternal disease, the effect of Lupus disease activity on the unborn baby and the safety of medicines during pregnancy and breast feeding.

During pregnancy, women with Lupus should have extra monitoring in the form of an individualised plan made by the Obstetric Team. LUPUS UK has an excellent guide to pregnancy that patients may also find useful on their website [www.lupusuk.org.uk](http://www.lupusuk.org.uk).

We would encourage you to discuss your choices regarding contraception and any future pregnancy plans with your clinician wherever possible.

We are planning an interactive morning later in the year and will discuss further issues of interest for all our patients with the usual informal lecture and question and answer format.

We hope that you will be able to join us for this event and we will provide further details as soon as possible.

*Carol Brumpton - Lupus Nurse Specialist*

## Medic Alert

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Medical Alert Bands tailored to your condition and medication are now in affordable forms prices starting from £1.95



<http://www.theidbandco.com/Rubber-Medical-Bracelets>

The ID Band Company Limited  
Unit 9 Oak Drive  
Lionheart Enterprise Park  
Alnwick  
NE66 2EU  
United Kingdom



Tel: 0800 999 3669

## Foot Care - Shirley Merritt

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Following research undertaken to look at problems lupus suffers experience with their feet , it is becoming more routine to be offered referral to chiropodist/podiatrist .



This has been very helpful for me, having been referred by the specialist nurse. The wait to be seen was not long and the treatment and advice received as a result has been beneficial both to my foot comfort and avoidance of further infection.

Myself and others locally took part in research to determine the effects of lupus on the feet. This is a great example of how research can have a positive outcome to improve the patient care offered.

## Calling all Ebay Sellers!

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Do you sell on EBAY?



Lupus UK have a site to buy or sell your items where a percentage of the proceeds can be donated to the work of Lupus UK – copy the links

<http://www.lupusuk.org.uk/sell-for-lupus-uk-on-ebay/>

[http://www.ebay.co.uk/egw/ebay-for-charity/charity-profile/?np\\_id=193747](http://www.ebay.co.uk/egw/ebay-for-charity/charity-profile/?np_id=193747)



## May 10th is World Lupus Day

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There is no boundary to the impact of lupus. Lupus is a global health problem that affects people of all nationalities, races, ethnicities, genders and ages. Lupus can affect any part of the body in any way at any time, often with unpredictable and life-changing results. While lupus knows no boundaries, knowing all you can about lupus can help control its impact.



### *About World Lupus Day*

World Lupus Day is sponsored by the World Lupus Federation, a coalition of lupus patient organisations from around the world, united to improve the quality of life for people affected by lupus. Through coordinated efforts of its global affiliates, the World Lupus Federation works to create greater awareness and understanding of lupus, provide education and services to people living with the disease, and advocate on their behalf. Learn more at [worldlupusfederation.org](http://worldlupusfederation.org).

World Lupus Day serves to call attention to the impact that lupus has on people around the world. The annual observance focuses on the need for improved patient healthcare services, increased research into the causes of and cure for lupus, earlier diagnosis and treatment of lupus, and better epidemiological data on lupus globally. World Lupus Day serves to rally lupus organisations and people affected by the disease around the world for a common purpose of bringing greater attention and resources to efforts to end the suffering caused by this disabling and potentially fatal autoimmune disease.

### *About World Lupus Day and Dorset*

Every year we try to have a Lupus Information Stand in a couple of the Dorset hospitals on May 10 – this year we are planning to be at Dorchester County Hospital and Bournemouth General Hospital.

If you are able to help on that day – please contact Helen Bifield 01202 696299 (for Bournemouth) or Rosemary Smeeton 01305 761454 (for Dorchester) Many thanks.

## Dates for your diary - cut off and stick on your fridge

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**Sat April 1st** - Coffee Morning at Haskins Garden Centre, Nr Ferndown BH22 9DG - 11-12.30pm

**Sat May 6th** - Hampshire Lupus Information Day at The guildhall, Winchester 1.30pm

**Wed May 10th** - Stands at Bournemouth Hospital & Dorchester Hospital - 10-3pm

**Sat May 27th** - Boutique in a Bus at 2 Kindle Cottage, Puddletown, Nr Dorchester, DT2 8SJ - 2-4.30pm

**Sun June 11th** - Manor Farm Open Gardens - Hampreston - 1-5pm

**Sat June 24th** - Coffee Morning at Haskins Garden Centre, Nr Ferndown BH22 9DG - 11-12.30pm

**Sun July 30th** - Manor Farm Open Gardens - Hampreston - 1-5pm

**Wed 3rd Aug** - Manor Farm Open Gardens - Hampreston - 1-5pm

**Sun Aug 13th** - Manor Farm Open Gardens - Hampreston - 1-5pm

Lupus UK Reg Charity No. 1051610

National Office: St James House, Eastern Road, Romford, Essex RM1 3NH

Tel: 01708 731251 Fax: 01708 731252

# COFFEE MORNINGS

Saturday 1 April 2017

*And*

Saturday 24 June 2017

11am—12:30pm

At HASKINS GARDEN CENTRE  
Near Ferndown [BH22 9DG](#)

The last coffee morning at Haskins was so successful we thought it is a good place to meet again—

*There will be a coffee morning in Dorchester in November—  
details to follow in the Autumn newsletter*

Information leaflets will be available