



# DORSET LUPUS GROUP NEWSLETTER

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## Regional Co-ordinators

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## Patrons

Dr Neil Hopkinson DM FRCP

Christopher Chope OBE MP &  
Christo Chope

*A word from your Coordinator...*

Hello everyone

Just a reminder - October is also Lupus awareness month and we are planning to have stands at the Bournemouth and Christchurch Hospitals as before - dates and times in the newsletter.

We had a great turn out for the last coffee meet up at Haskins and hope to see more of you again at the next one at the end of November - see pictures below.

Well done to Tamsin for her brilliant efforts doing the 4 seasons Wolf Runs final amount raised to be confirmed after her last run in November - If you have any fundraising events taking place please let me know so we can publicise them accordingly and likewise after an event please send any photos or articles so we can get those published as well.

You can contact me on 07815 581481 or [sean@dorsetlupus.com](mailto:sean@dorsetlupus.com)

*Sean :)*



## Hampreston Teas and NGS Garden...

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Debbie Steel and her (small) team of volunteers have done another fantastic season running the teas at Hampreston. They raised a fantastic total of £1545.91 this year - the highest amount yet, so huge congratulations to them all. However they are desperately in need for more volunteers to help with tea/coffee making, service and a bit of washing up. The dates for 2020 are as follows:

**Sat Feb 22nd 10 am until 1 pm**

**Sun Feb 23rd 1 - 4 pm**

**Sun June 14th 1 - 5 pm**

**Sun July 26th 1 - 5 pm**

**Either Tue Aug 4th or Wed 5th (TBC) 1 - 5 pm**

**Sun 9th Aug 1 - 5 pm**

If you are available for one or more of the above dates please contact Debbie direct via [debbie.steel@outlook.com](mailto:debbie.steel@outlook.com). It is a lovely afternoon and you will get a chance to have a look round Anne's wonderful gardens as well!

For those who don't know Anne Trehane was a Rheumatology practitioner who wanted to continue helping Lupus sufferers and opened up the Tea Room at the family farm help allowing all proceeds of sales from tea, coffee, cake and soup to go to Lupus. The Manor House is part of the Open National Garden Scheme and has a traditional farmhouse garden designed and cared for by 3 generations of the Trehane family through over 100yrs of farming and gardening at Hampreston. The garden is noted for its herbaceous borders and rose beds within box and yew hedges, mature shrubbery, water and bog garden. It is open for hellebores and snowdrops in February. There will also be Dorset Hardy Plant Society sales at the openings with Hellebores for sale in Feb.

Address is: Manor Farm, Hampreston, Wimborne, Dorset BH21 7LX

## Keep in Touch...

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If you know of anyone who is going through a bad time, in hospital, struggling at home, please let Sean know so a card can be sent, on behalf of DLG, to let them know we are thinking of them. Sean's email address is [sean@dorsetlupus.com](mailto:sean@dorsetlupus.com) Alternatively phone on 07815 581481.

It's always nice to receive a card.



## Online Survey Results...

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Lupus UK conducted a short online survey about hydroxychloroquine. Within two weeks they received 1,000 responses and they have now analysed the results and published findings. They are very grateful to Prof Caroline Gordon and Rebecca Gilman (Lupus Research Clinical Nurse Specialist) for their input and guidance.

You can read about the results and LUPUS UK's recommendations on our website at <https://www.lupusuk.org.uk/hydroxychloroquine-survey-results/>

## 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



## Hydroxychloroquine Availability Update...

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- 1) Teva UK Limited have discontinued production of their version of generic hydroxychloroquine tablets.  
- More information and advice about this is available on the website at <https://www.lupusuk.org.uk/teva-hydroxychloroquine/>
- 2) Zentiva have been experiencing a systems issue in distribution centres which has been affecting supply for a few months. Due to all the reports they have now prioritised this medication and orders should be fulfilled with wholesale suppliers by the end of July. Again, more information and advice about this is on our website at <https://www.lupusuk.org.uk/zentiva-hcq/>  
The Lupus UK website reflects this new information - <https://www.lupusuk.org.uk/hydroxychloroquine-prescriptions/>
- 3) If you require the Zentiva version of hydroxychloroquine tablets and your pharmacist has any difficulty obtaining them, the product description is: "**HYDROXYCHLOROQUINE SULPHATE (ZENTIVA) 200MG FILM COATED**" and the '**PIP number**' (product code) is **1201730**. If for any reason they cannot find the product on their system they can ring the customer service line on **0800 854 431**.

## October is Lupus Awareness Month...

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As you are aware, October is Lupus Awareness month. We will be holding Information Stands at Bournemouth Hospital in the atrium area on Thursday 24th October from 10am to 1pm and also at Christchurch Hospital near the blood test waiting area on Wed 30th October from 10am to 1pm. Please drop by and have a chat.

## A Lupus Guide for Nurses and Health Professionals...

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The brand new, updated and improved edition of 'Lupus – A Guide for Nurses and Associated Health Professionals' has been received from the printers and is in stock at LUPUS UK National Office. We are extremely grateful to Sr Rebecca Gilman (Lupus Research Clinical Nurse Specialist) and Professor Caroline Gordon for the immense amount of work they have poured into this revised publication.

If any of you require copies to be posted for your local Drs surgery/local hospitals, please email Mary ([mary@lupusuk.org.uk](mailto:mary@lupusuk.org.uk)) and she will be happy to arrange this for you.

## Lupus Medication Availability in a 'No-Deal' Brexit...

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### What impact could a "no-deal" Brexit have for people with lupus?

It is very difficult to predict exactly what might happen to health and care services used by people with lupus and associated conditions if the UK leaves the EU without a deal. However, the Government, the Department for Health and Social Care and the NHS have been working with drug and medical device manufacturers to put in place plans so that supplies of medicines are stockpiled in the short term.

We are aware that this has included seeking advice from companies that manufacture drugs for lupus. The Department for Health and Social Care (DSHC) has established a 'hotline' for suppliers to the NHS to use if they experience any disruption to deliveries as a result of Brexit, and they are also working with their counterparts in Scotland, Wales and Northern Ireland to support them in any preparations.



### Do I need to stock-up on any medication I'm taking, or ask for my prescription to be changed?

The Government has made it clear that it **does not recommend people to keep stocks of medication**, and it has issued advice on this to the NHS and other healthcare providers. The majority of drug suppliers have put in place contingency plans to ensure at least a six week supply, as requested by the Government, with many holding stocks for a much longer period. The NHS in Scotland has also set up a specialist group to look at any potential medicine shortages resulting from a "no-deal" Brexit.

If your pharmacist is unable to provide the medication you have prescribed, they may suggest an alternative or ask you to see your GP to have your prescription changed. If there's anything you'd like to know about changes to your medication, it is important you speak to your GP or healthcare professional in charge of your care.

In the short term, it is very difficult to fully understand the potential impact of a possible "no-deal" Brexit and how it might affect the availability of medicines. However, we will continue to monitor the ongoing situation to ensure that the needs of people with lupus are considered and we will update our information and advice accordingly. The information on the Lupus UK website will continue to be updated as we know more.

If you have any questions that are not answered here, please contact LUPUS UK and we will do our best to be of assistance.

*Article courtesy of Paul Howard, Lupus UK*

## Flu Vaccinations in Lupus...

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Flu season will soon be upon us once again. To answer any questions you may have about the influenza vaccine Sue Brown (formerly lead specialist nurse in Rheumatology at the Royal National Hospital of Rheumatic Diseases in Bath), Jane Hollis (Lupus Nurse Specialist at Addenbrooke's Hospital), Prof David Jayne (Professor of Clinical Autoimmunity at Addenbrooke's Hospital), Dr Kate Armon (Consultant Paediatric Rheumatologist at Addenbrooke's Hospital) and Dr Rona Smith (Clinical Lecturer in Nephrology at Addenbrooke's Hospital) have written the following article for us.

### **Why is the flu jab important in lupus?**

For most people, flu is not usually serious and recovery is often expected within a week. However, for certain groups of people, especially those with diseases of the immune system such as lupus, symptoms can last longer and there could be an increased risk of developing complications such as bronchitis or pneumonia. The flu vaccine is available free of charge to everyone with lupus in the UK in order to protect you from the flu and any potential complications.

### **Will the flu vaccine cause my lupus to flare?**

Sometimes the vaccine may make your symptoms a little worse, but this should settle in a few days. You cannot get flu from the adult flu vaccine as it does not contain live viruses.

### **Am I entitled to a free influenza vaccination because of my lupus diagnosis?**

Yes. Patients who have lupus fall into the high risk group. They may be on immunosuppression, on steroids, and lupus disease will classify as being immunocompromised.

### **What do I do if my GP Surgery won't give me a free influenza vaccine?**

Discuss with your lupus team at the hospital who could send a copy of Department of Health guidelines to your GP with a letter of recommendation.

### **How does the flu jab work?**

The flu jab causes your body's immune system to make antibodies to fight the flu virus. Antibodies are proteins that recognise and fight off germs that have invaded your blood, such as viruses. If you catch the flu virus later on, the immune system will recognise it and immediately produce the antibodies to fight it. It may take 10-14 days for your immune system to respond fully after you have had the flu injection. The antibodies against the flu strains will gradually decrease over time and the flu strains can change from year to year.

### **I was immunised last year. Do I need to be immunised again this year?**

The flu virus continually changes and different types of flu virus circulate each winter, so it is recommended that you should have the latest strain of flu vaccine by intramuscular injection every year. The World Health Organisation (WHO) makes an assessment every year of the strains of flu virus that are most likely to be circulating during the following winter. Based on this assessment, WHO recommends which three flu strains the vaccines should contain for the following winter.

### **Can the flu vaccine be given if I am on other medication?**

Yes. The vaccine can safely be given when you are taking most medications. Discuss this with your doctor or nurse if you are unsure about this. Rituximab treatment can reduce response to vaccinations. If you are receiving Rituximab you should have your vaccinations one month pre Rituximab or four months after your infusion.

*Article courtesy of Lupus UK - full article can be read on the LUPUS UK website*



## Coffee & Chat...

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There will be a coffee and chat in the back room at Haskins Garden Centre, Ferndown, for 11 am on Saturday 30th November at 11am.

There will be a 'DORSET LUPUS GROUP' sign on the table and we will have some Lupus information available.

Looking forward to seeing you.



**Haskins address:** Haskins Garden Centre Ferndown, Longham, Ferndown, Dorset BH22 9DG

## Tai Chi...

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A Tai Chi and Mindfulness Course has been arranged by one of our members. This will be a 6 week course for beginners - all welcome. The cost is £48 for the 6 weeks or pay as you go for £10 a session. The course will start on Tuesday November 5th at 6.30 pm - 7.30pm held at The Beehive Studio, 129-131 Belle Vue Road, Southbourne BH6 3EJ. Please just turn up on the day and we hope to see a few of you there!

## Bits you might have missed...

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Lupus UK were recently contacted by the agent of Cat Burns, an eighteen year old singer/songwriter from South London. Cat's mum has lupus and she is keen to help raise awareness of the disease and support the charity using her platform. She is interested in being an ambassador for the charity and so to get things started they did a short interview to learn more about her. Cat has agreed to share her story, which you can now read in an excellent feature written by Chanpreet at <https://www.lupusuk.org.uk/cat-burns-talks-lupus/>. Cat and her mum have been invited to attend the London Lupus Information Day in October.

Kelle Bryan (of pop group Eternal) was on Loose Women on ITV1. Kelle spoke briefly about her lupus, which gives additional exposure and awareness for the disease. You can watch the section which begins at 21:50 on the ITV player at <https://www.itv.com/hub/loose-women/1a3173a3248>.

BBC Radio 4 Woman's Hour. Rashida Hardy (25) from London was thrilled at the opportunity to help raise some awareness of lupus and her interview was broadcast in April. You can listen to the segment (starting at 09:28) online at <https://www.bbc.co.uk/programmes/m0003rlk>.

A new short film documentary called 'Ill, actually' is now available to view online on the BBC iPlayer at <https://www.bbc.co.uk/iplayer/episode/m0003fqk/born-digital-first-cuts-5-ill-actually>. 'Ill, actually' presents the stories and experiences of three young people living with invisible illnesses, one of whom is Jameisha who has lupus. The documentary does a good job of portraying some of the impact illnesses like this can have on the lives of young people, and the different perceptions around them.

The Sun newspaper featured an article about invisible diseases, including a photoshoot and interview with LUPUS UK Young Contact, Amy Baker. You can also view the article online at <https://www.thesun.co.uk/fabulous/8709469/invisible-illness-battle-selma-blair-ms/>.

Lupus UK Reg Charity No. 1051610

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

Tel: 01708 731251 Fax: 01708 731252

## Fundraising...

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Our Editor Tamsin has been busy this year fund-raising for two charities - Lupus UK being one of them. She has been taking part in WOLF RUN 2019 which is a 4 season 10km trail run through woods, obstacles, lakes and fields. The last event, the winter run 10k is taking place the first weekend in November and so far to date she has raised just over £1100.

As many of you know Tamsin has been involved with the Dorset Lupus Group for the past 10 years and was diagnosed with Lupus at the age of 16. This has been a real personal challenge for her in every aspect. If you would like to support and sponsor Tamsin (she would be very grateful!) - her story and the just giving page link is: <https://uk.virginmoneygiving.com/TamsinWilliams3>



*From L to R:  
After Spring  
Wolf ; Before  
& After  
Summer Wolf;  
Before  
Autumn Wolf*

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

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**October** - LUPUS AWARENESS MONTH

**Thurs Oct 24th** - Bournemouth Hospital Information Stand - Bournemouth Hospital foyer area - 10-1pm

**Wed Oct 30th** - Christchurch Hospital Information Stand - Christchurch Hospital (near the blood test wait area) 10-1pm

**Tues Nov 5th** - Tai Chi classes, every Tuesday for 6 weeks 6.30-7.30pm at The Beehive Studio, Southbourne

**Sat Nov 30th** - Coffee and Chat - Haskins Garden Centre, back room in the cafe area - 11am