



DORSET LUPUS GROUP NEWSLETTER

WINTER EDITION 2012



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OUR PAGE AND GET INVOLVED!**

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will get back to you.

PATRONS

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

SPONSORS

If you would like to sponsor
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would, please get in touch.



CHAIRS MESSAGE

Hello everyone. I wish you all a Very Happy (and hopefully pain-free!) Christmas full of friendship & a really enjoyable New Year full of Promise for the year ahead. Tamsin's got a shorter newsletter for you this time as we're moving onto a new schedule and it's only a few weeks since we sent the last one out. We've got a lot of good things going on around the Group for the New Year. First up after Christmas of course will be our Annual Luncheon in mid-January and I would like to personally invite each and every one of you to join me and the rest of us at this special get-together to set the year off – see event for details. It would be especially nice to meet and greet some of you new members who have joined Lupus UK and hence our Group too in recent months ... and also to

renew friendship with some of you whom I haven't seen in a while.

After that we've got a whole series of events and activities planned for 2013 and we're also working on some other ideas on your behalf – we'll write and tell you about them as the plans develop!

I would also like to extend my thoughts and best wishes to those of you whose health isn't quite what you would wish for at this time of the year, and if there's anything at all that any of us in the Group might be able to do to brighten things up for you then PLEASE get in touch with one of us – there's nothing more special for any of us than being able to bring a little help and friendship to others over this special season.

With my very warmest greetings,

EDITORS MESSAGE

Hi all,
Well that time of year is nearly upon us again - I simply cannot believe where this year has gone!

Just a short newsletter before Christmas to keep you up to date. I myself have been extremely busy with my day job, family commitments not to mention the Christmas organization - which I'm sure

many of you can relate to!
Please remember as from January we will be changing to 3 newsletters a year in April, August and December, so any contributions to be with me two weeks prior to the 1st of the month.

I would also like to send huge get well wishes from all the committee and our members to Janet Bourne as she



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has been very poorly recently and wishing her a speedy recovery in time for Christmas.

Take care everyone and wrap up warm in this wintery weather I wish everyone a very merry Christmas and a prosperous start to the new year 2013.

Tamsin x

A Review of Past Events...

MILBOURNE PORT COFFEE & CHAT OCT 27TH

Janet Heath (pictured with her raffle win) kindly organised a very successful coffee and chat morning in Milbourne Port. I'm sure it would be well received to have another one there in the near future.



Some pictures from the Milbourne Port meet up

LANGTON ARMS COFFEE & CHAT NOV 10TH



A good turn out— thank you to all who came and a successful speaker April Whalley, who also has Lupus herself and practises in alternative therapy regularly holding local classes. April spoke on 'The Holistic Approach to Lupus' which was very well received and I think many people took away a lot from this.

If you would like to talk to April more or have a look at the types of therapie she offers please take a look at www.aprilwhalley.com



CHRISTMAS CARDS!

Yes its that time again and we have a stack of Christmas cards available for you.

Debbie has once again very kindly stacked up on the Christmas cards to save on postage and they will be available to purchase at the next coffee and chat meeting. There is a limited amount available so please don't leave it until the last minute!



Future Events...

CHRISTMAS COFFEE TIME AT THE HOWARD CENTRE, CHRISTCHURCH HOSPITAL ON SAT 8TH DECEMBER AT 10.30AM

Come along to our always popular and well attended christmas coffee time, we will be having a Christmas raffle, cakes and treats, last year someone even bought a few bottles of fizz! Please join us for a friendly festive morning.

NEW YEAR LUNCHEON AT MIRAMAR HOTEL, BOURNEMOUTH ON SUNDAY 13TH JANUARY 2013 AT 12PM

3 course meal will be £18.95 (same price as the last few years!). Please send a deposit of £8.95 per head to Debbie Steele - remainder to pay on the day. This event is always

well attended and much fun so we hope to see you there!

COFFEE TIME AT THE HAVEN HOTEL, SANDBANKS, POOLE BH13 7QL ON SAT 16TH FEBRUARY AT 10.30AM

Come along to our popular venue with a beautiful view. All the usual things and a chance to catch up after the busy Christmas period.

OPEN GARDEN NGS SCHEME AT MANOR FARM, HAMPRESTON, WIMBORNE, BH21 7LX BETWEEN 1.00P.M. AND 5.00P.M. DATES - SUNDAY FEBRUARY 24TH 2013 FROM 12.00—4.00PM.

Anne & Guy Trehane have invited us to help serve the refreshments. All monies collected will go to Dorset Lupus.

Please come along, either to help us serve tea and cake, or to view the magnificent garden.

ANNUAL AGM & COFFEE TIME AT PORTFIELD COMMUNITY HALL, PORTFIELD ROAD, CHRISTCHURCH BH23 2AQ ON SAT 6TH APRIL 2013 AT 10.30AM

Come along to our annual AGM, Join the committee or show your support in another way—we are always looking for help and volunteers. A speaker will be arranged for afterwards and we always try and keep these short and sweet. Refreshments available as always.

WORLD LUPUS DAY AT 10TH MAY 2013

Are you organising anything for this - coffee morning, lunch etc—let me know and I can put it in the next

HealthUnlocked

Connect with LUPUS UK and the people affected by lupus

- See what other people with lupus are doing and thinking
- Answers from people within the lupus community

Tools to help you make choices that are right for you. Join a friendly online community of other Lupus sufferers, write a blog or ask a question - it is totally up to you.

<http://lupusuk.healthunlocked.com>

PLEA FOR HELP!

Helpers required for the Open Garden on Sunday 24th February

- without help doing the teas/ serving cakes/ washing up... it can't go ahead as the Trehanes rely on help from the Dorset Lupus Group - only fair as we get the proceeds!

If you can lend a hand please call Debbie with your preference on times (1-3 pm or 2-4pm) to help.

Your Story

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

Coffee Groups around the county

We are trying to set up some little coffee groups around the county to get more members involved that wouldn't usually come to the meetings or cant get there for one reason or another. If you would like to meet up with others in your area for a coffee and chat please call Tamsin or Gerry and we will try and get in touch with others in your locality

Doctor H's Spot...



I am writing this article from Washington DC in sunny, if cold, North East USA. Why? 14000 Rheumatologists from all over the world have gathered for the 29th meeting of the American College of Rheumatology annual scientific meeting. It is a place where new research is presented, and debate occurs about existing treatments. It is place to think more freely outside the normal pressures of clinical life and, I think importantly, a place to chat with other rheumatologists about life in their hospital and how they are treating patients.

As you can imagine there the meeting covers all aspects of rheumatic disease and Lupus has featured heavily. Belimumab (Benlysta) is a drug we have talked about before at Lupus AGM meetings. It still isn't available in the UK but has been used in the USA for some time and presentations on this were plentiful. One talk detailed the results of treatment after 7 years. All of the patients presented would have started the drug in a research study and of those 449 patients originally started in this particular study 177 patients were still receiving it. This is not a cure for Lupus but significant improvements were seen in a number

of organ systems. In addition, the average dose of steroids that patients were taking in the study fell and the number of flares of Lupus improved. There were some side-effects though, for example 10% of patients experienced infusion reactions and in 1% these were quite serious (the drug is given as a regular intravenous infusion).

We still haven't recruited any Lupus patients in to the international research study that Christchurch hospital is involved with. The study of epratuzumab is also given intravenously and looks a promising treatment for patients with active Lupus patients who continue on steroid medication. If you feel you might be a candidate for this study do speak to your specialist about it. We are also involved in a national study looking at causation of Lupus which involves a detailed questionnaire about possible causative factors and Carole Frosdick, Research Nurse can give more information about this.

I wish you a Happy Christmas and New Year!

Dr Neil Hopkinson



Festive Facts...

□ Christmas dinner provides the perfect opportunity to indulge your body with a feast of healthy goodies and hit those 5-a-day veggie targets. Pile your plate full of colourful veggies as they're packed full of important vitamins and nutrients.

□ On average over Christmas, the UK will indulge in approximately 5.5 million jars of mincemeat, 12 million jars of pickles and 6.5 million jars of cranberry sauce.

□ 15,000 tonnes of sprouts will be bought in the UK during the Christmas period and during the festive season, each person will eat an average of 15 sprouts.

□ 175 million mince pies will be bought from Britain's supermarkets

this Christmas. If these were stacked on top of each other, they would stretch 3,262 miles high – that's nearly 600 times the height of Mount Everest!

□ Mince pies get their name from their original filling which contained minced meats as well as fruits and spices The pastry around the pie was said to represent the manger in which Jesus lay.

□ Nearly 3,000 tonnes of aluminium foil will be used to wrap Christmas turkeys this year

□ At Christmas the UK will indulge in around:

□ 19,000 tons of turkey □ 1,200 tons of parsnips

□ 120,000 tons of potatoes □ 7.5 million carrots

□ 1,600 tons of chestnuts □ 16 million packets

□ 11 million Christmas cakes □ of stuffing

New year newsletter dates...

The new year brings new things and the newsletter dates will now be 3 a year - coming out the first week in April, August and December.

If you would like to write an article or submit a photo please can you send it to Tamsin@dorsetlupus.com by the 16th of the previous month.

Thanks



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.



VACANCY

For Vice Chair person

DorsetLupusGroup

If you are interested or would like more information please get in touch with Gerry Gray.

Christmas Recipes...



Chicken Gumbo

Based on the classic Cajun dish, can be made ahead and reheated to save time.

Serves 4 Cook 40 mins

INGREDIENTS

- 1tbsp olive oil
- 500g skinless chicken thighs cut into chunks
- 1 onion diced
- 2 garlic cloves, finely chopped
- 2 sticks celery, finely diced
- 1 green pepper, diced
- 1 bay leaf
- 2 tbsp plain flour
- 1 tbsp Cajun seasoning
- 1x 400g tin chopped tomatoes
- 280ml chicken stock
- 175g okra or extra green pepper, cut into chunks
- 2 tbsp finely chopped sage

METHOD

Heat oil in large pan. Add chicken and cook for 5 mins to brown all over. Remove chicken and set aside.

Add onion, garlic, celery, pepper and bay leaf to pan and cook 5 mins. Return chicken to pan, then stir in flour and Cajun seasoning and cook for 30 seconds.

Add the tomatoes, stock, okra and sage, bring to boil then turn down to a simmer, cover and cook for 10 mins.

Remove lid and cook for another 5 mins, season to taste. Serve with crusty bread.

Bacon and Eggs Kedgeree Style

This twist on bacon and eggs is great to feed a crowd.

Serves 4 Cook 20 mins

INGREDIENTS

- 4 eggs
- 2x 250g packs microwave rice
- 1 tbsp olive oil
- 1 onion, finely chopped
- 180g oak smoked lardons
- 1/4 tsp cayenne pepper
- Handful fresh parsley, chopped

METHOD

Bring a pan of water to the boil and cook the eggs for 6-8 mins. Drain and cool in running cold water, then peel and quarter.

Cook the rice following the packs instructions.

Meanwhile heat the oil in a frying pan on a medium heat and cook the onions and lardons for 5 mins until

just becoming golden. Stir in cayenne pepper and cook for another minute.

Stir through the cooked rice and serve topped with the quartered eggs and fresh chopped parsley.

Clementine fizz served with pomegranate seeds

Something special for the big day!

Serves 6 Prep 5 mins

INGREDIENTS

- 10 Clementine's
- 3 tbsp pomegranate seeds
- 1x 750ml bottle sparkling wine, well chilled

METHOD

Squeeze the juice from the Clementine's - you'll need about 300ml(1/2 pint), pour through a sieve to remove any pith or seeds.

Divide the juices between 6 champagne flutes and add a spoonful of pomegranate seeds to each. Top up with the sparkling wine and serve.

* If you cant find fresh pomegranates or seeds, simply add a dash of pomegranate juice.

* For drivers try swapping the fizz for soda water (more bitter taste) or white schloer (sweeter taste).

MedicAlert Foundation

MedicAlert 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 MedicAlert 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 hr 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 MedicAlert on **0800 581420** email: **info@medicalert.org.uk** or see **www.medicalert.org.uk**.



WAITROSE SCHEME

The Waitrose scheme 'Community Matters' divides £1000 between three local good causes the public choose. If you have a Waitrose near you, please pick up a leaflet in store to nominate our good cause.

Has anyone applied for this? We would be interested to hear from you.

If you would like some help filling in the form please call Tamsin on 01202 470211.

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!



Trust Fund



The Dorset Lupus Group have a trust fund with just under £2,000 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, 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 470211 or write to 23 Liberty Court, Dragoon Way, Christchurch, BH23 2TZ Dorset.

Strict confidentiality will be followed at all times.

KEEP IN TOUCH

If you know of anyone who is going through a bad time, in hospital, struggling at home or celebrating a special event, please let me know so I can send them a card, on behalf of DLG, to let them know we are thinking of them. My email address is smiley.face@sky.com Alternatively phone me on 01202 535123. It's always nice to receive a card.

Keep the birthday dates coming so we can send a card on your birthday.

Smiley

Contacts and Hospital Buddies



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 and talk to one of our friendly contacts.

We have a **Hospital Buddy** service, where a member of the Group will attend any appointments or test at the hospital to help support you,

even if its just to remember what the Dr has said!

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

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

LEAFLETS & POSTERS



We have got some brightly coloured leaflets for the Dorset Lupus Group – describing a bit about Lupus and symptoms along with details of the committee and our group. We also have some Lupus UK posters with information about the Group for Doctors surgeries, libraries, notice boards etc. If anyone would like a copy for themselves or to give out please get in touch with Gerry or Tamsin and we can arrange to distribute them to you.

Could you put some in your local Doctor's Surgery, library, church or Information Office?

Top tips for a healthier Chrimbo...



There are many ways that you can enjoy a healthy and nutritious Christmas so here's how to merrily munch your way through the festive season.

- Try to eat breakfast on Christmas day as this will fill you up and you will be less likely to snack on Christmas choccies!
- Serve Christmas dinner with heaps of veg for a balanced meal which helps towards the target of at least five fruit and vegetables a day. Fruit and veggies are a good source of nutrients and they contain hardly any fat!
- Microwave, steam or roast veg to preserve more vitamins. Cook and serve without salt. Try other flavourings like pepper or fresh herbs instead.
- Cut potatoes for roasting into larger chunks – they'll absorb less fat. Roast in a small amount of unsaturated (e.g. sunflower) oil for a healthier choice.
- Turkey meat is a lower fat choice for Christmas dinner; traditionally goose was eaten but is much higher in fat.
- Try making your own gravy instead of using cubes or granules which tend to be high in salt.
- At tea time go for turkey sandwiches, made with thickly cut bread and filled with spinach and watercress.
- When it comes to the traditional

Christmas pudding, for a healthy change, instead of serving it with brandy butter, try some natural yoghurt or even some fresh fruit.

- If you're having sweet treats like sweets, cake and crisps, try having them in smaller amounts instead.
- During the party season, it's easy to drink lots of sugary fizzy drinks but opt for water or fruit juice when you can or add a slice of lemon or lime to water to make it a bit more interesting.
- For healthy snacks, go for unsalted nuts, dried fruit or satsumas.
- Avoid feeling uncomfortably full by eating more slowly.
- Get active rather than slump on the sofa - take a brisk walk, play an indoor game or maybe just crank up the music and dance away those calories! For those less able and less mobile, a gentle stroll in the park, along the sea front or in the New Forest to blow the cobwebs away is just as good!

DID YOU KNOW...

The average person eats a gut busting average of 7000 calories on Christmas Day and it would take roughly 780 minutes of running to burn off those calories!

Dates for your Diary



Dec 8th Xmas Coffee time at The Howard Centre, Christchurch Hospital, 10.30am

Jan 13th 2013 Xmas/ New Year luncheon at The Miramar, 12pm

Feb 16th Coffee Time at The Haven Hotel, Sandbanks, poole at 10.30am

Feb 24th 2013 NGS Open Garden Scheme at Manor Farm, Hampreston

April 6th 2013 Dorset Group AGM at The Portfield Community Hall, Portfield Road, Christchurch at 10.30am

May 10th 2013 World Lupus Day

SHARE YOUR NEWS...

Do you have anything that you would like to share in our newsletter.....photos of events, congratulations...ANYTHING!

Please email it to

Tamsin@dorsetlupus.com

Your Committee...

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