



DORSET LUPUS GROUP NEWSLETTER



SPRING EDITION 2013

CHECK OUT OUR WEBSITE UPDATES

**ARE YOU ON FACEBOOK?... JOIN
OUR PAGE AND GET INVOLVED!**

A quick look...



Events Past and Future

World Lupus Day

DIY SOS

Costas anyone?

Message in a Bottle

Winter Blues

Drop in Clinics

Obituary - Patricia Vaughan

Springtime Recipes

AGM notice

Contacts and Buddies

Annual Conference & AGM notice

Diary Dates!

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LUPIE BEAR...



Say hello to the new Lupie Bear—he is available from the Lupus UK shop at only £2.50 (plus P&P). How cute is he! Why not get one to take on your hols this year and send in a photograph of the little fella on holiday—we will print all the photos sent in.

EDITORS MESSAGE

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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.



Hi all,

Once again the newsletter has come around so quickly I am not sure where the first quarter of the year has gone to!

I myself, am busy at work and the weeks are just flying by. Unfortunately the weather doesn't seem to be keeping up, but fingers crossed it will be warmer soon.

The shorter newsletter this time is a reflection of my own workload, and I hope to add some extra tidbits in next time.

Unfortunately our AGM had to be cancelled at the last minute due to our Chair Gerry being unwell - he is on the mend now and feeling much better. The new date for the AGM is 11am on the 11th May at Portfield Hall in Christchurch as before - please try to come and support your local committee, we try our best for you and its nice to have the feedback.

Dr Neil Hopkinson has agreed to speak after the AGM (and coffee and cakes!) and I'm sure as always it will be interesting and informative.

If anyone would like to stand on the committee - whether that's taking an active part or being there to help when you can we would like you to get in touch. If you could let our Secretary David Mays know beforehand - contact details on the left of the front page.

Also we have arranged a walk along Bournemouth Pier (with a coffee and cake in a café stop of course) on 13th July so hope to see you there!

In the meantime keep well and enjoy the spring (at last!)

Tamsin x

A Review of Past Events...

HAVEN HOTEL, SANDBANKS COFFEE & CHAT FEB 16TH

A beautiful fresh sunny day overlooking the water at sandbanks. The morning was well attended and everyone was in high spirits and hopes for the spring due to the weather (which unfortunately didn't last long!). A vast array of danish pasties and croissants were provided along with copious amounts of tea and coffee, along with a huge amount of conversation and catching up!



AGM APRIL 6TH

Unfortunately had to be cancelled due to an unexpected illness however has been rearranged (see below).

Young Lupies...

LUPUS UK now has a secure forum for young people with lupus (16-24). If you'd like to chat with other understanding young people about your life with lupus, or anything else, then you can request to join. For the safety of all members you will be required to undertake an identity check.

For more information about joining, please email nicola.daly@uclh.nhs.uk

Costa's anyone?..



If anyone would like to meet up for a chat around the county and would like to be introduced to nearby members please let me know and I will do my best to hook you up with local people to you.

I recently met up with a lady who has lupus local to Christchurch who doesn't usually come to meetings. We had a lovely cappuccino, long chat and met someone new. It would be nice for others to do the same!

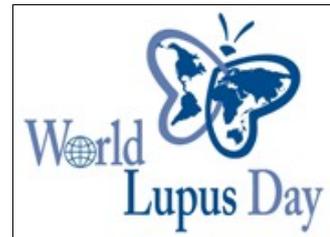
World Lupus Day...

This year, Lupus UK want **you** to take part in a World Lupus Day coffee morning on May 10th. Let's try to make it the biggest coffee morning ever for people with lupus! Get baking (or ask your friends to), pop on the kettle and invite people to join you and make a small donation to help raise funds and awareness.

Perhaps you can host a coffee morning at home, your local church or community centre, or maybe have a special coffee break at work?

For more information please email janine@lupusuk.org.uk and there are plenty of useful tips on hosting an enjoyable and successful coffee morning on the Lupus uk website!

Please send in your pics of events to Tamsin@dorsetlupus.com



Future Events...



WORLD LUPUS DAY ON 10TH MAY

Are you organising anything for this - coffee morning, lunch etc—let me know and I can put it in the next newsletter and have email shots sent out.

There will be a stand at Bournemouth hospital in the main atrium between 10am and 3pm - please come by and say hello.

“ ANNUAL AGM & COFFEE TIME AT PORTFIELD COMMUNITY HALL, PORTFIELD ROAD, CHRISTCHURCH BH23 2AQ ON SAT 11TH MAY 2013 AT 11AM ”

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.



NATIONAL CONFERENCE 12TH MAY

This year is being held at the Crowne Plaza Hotel in Chester. Please contact Lupus UK head office for a booking form if you would like to attend this year.



OPEN GARDEN NGS SCHEME AT MANOR FARM,

HAMPRESTON, WIMBORNE, BH21 7LX BETWEEN 1.00P.M. AND 5.00P.M. DATES - SUNDAY MAY 19TH, JUNE 10TH AND AUGUST 4TH 2013 FROM 1.00—5.00PM.

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.



COFFEE & WALK AT BOURNEMOUTH PIER SAT 13TH JULY. 10.30AM

We will be meeting at the end of Bournemouth Pier (Near Aruba) for a leisurely walk along the pier and there is a lovely place to stop for coffee/ tea at the end of the pier overlooking the water.



COFFEE & CHAT AT MILBOURNE PORT IN JULY

Date TBC



WALK THE EXTRA MILE TBC

Date TBC



COFFEE & CHAT AT TARRANT MONKTON LANGTON ARMS, NR BLANDFORD

IN NOVEMBER

Date TBC

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 19th May -

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 sad to report that Carole Frosdick, our Lupus Nurse, has left the department to start a new job altogether in Southampton. Many of you who have met Carole in her Lupus role or at Dorset Lupus group meetings will, like me, wish to send Carole all best wishes in her future career move.

We have not in recent years had specific funding for the Lupus Nurse role and in fact I originally funded Carole through a departmental charitable account raised through research activity and other income.

We are now busier than ever in the hospital seeing an increasing number of lupus patients and related connective tissue disease patients. Many of the patients I now see are coming from further away and this adds further to the normal patient numbers. Therefore, I believe with Carole's departure we should seek specific

funding for a Lupus Nurse through Lupus UK

The role of the Lupus Nurse is wide reaching and includes: education, patient management including troubleshooting blood tests and other investigations, helping to run a help line when patients run into difficulty, counselling, research, acting as a link between the hospital and other key workers including those in primary care or the local Lupus Group, etc., etc.!

All of you have done a lot locally to fund raise and contribute to the local hospital departments and I would hope that you would further support such an application. I will of course discuss this further at the next (postponed) Lupus meeting and I hope by then the weather will be warmer!

Take care,



Dr Neil Hopkinson

DIY SOS...



DIY SOS - THE BIG BUILD

DIY SOS: The Big Build is looking for major domestic renovation and construction projects.

If you are a homeowner, or know of a homeowner who has had a change in circumstances that has meant that major building work is now required, then we may be able to help.

The winning team of Nick Knowles, Billy the Spark, Chris & Jules and Irish Charmer Mark are all here to try and help and would love to hear from you.

Please apply via our online application form - can be found

on the Lupus UK website or via facebook page.

We are not looking for projects that are purely cosmetic. In past episodes we have built single and even double storey extensions. We've installed wet rooms, stair lifts and completely renovated and redesigned homes from the garden to the loft.

If this might be you please get in touch with them - you might be a lucky applicant!



Message In a Bottle...

Message in a Bottle (Data Link) is a scheme that gives the emergency services and health professionals details about your health, the medication you take and who to contact in an emergency. It is a scheme that the ambulance service (paramedics) the police, the fire service and all health professionals are aware of and enables them to know where to find your details especially if you are unable to communicate with them.

How does the scheme work?

Your details are stored in a clearly labelled plastic container, which is kept in your fridge. Two matching labels are displayed in your home, one on the outside of your fridge and one on the inside of your front door so it cannot be seen from the outside.

What do I have to do?

- Collect your free pot from a community pharmacist, GP practice or Age Concern
- Complete the form in ball point pen
- Fold the form and place it in the container
- On a separate piece of paper write down any other medication you maybe taking (i.e. bought medicines including complimentary medicines) and place in the container
- Each time you receive a repeat prescription, place the tear off slip into the container. If you do not have your repeat slip, write all the medicines you are taking on to a piece of paper and place this in the container - don't forget to take the old one out
- Place the container in the door of your fridge where it can be quickly and easily found - not in the freezer compartment
- Stick one of the labels on the outside of your fridge
- Stick one label on the inside of your front door so it is NOT visible from the outside but easily seen from

Winter blues...

Banish the winter blues in your home.

Are you eagerly waiting for the clocks to change so you can travel to and from work in day light? With less than 10% of the population now working outside in natural light, our ability to respond to nature's cues and regulate our body clocks has changed. This has resulted in an increase in light deficiency symptoms. Seasonal Affective Disorder, SAD or the Winter Blues is now a recognised medical condition. According to <http://www.sad.org.uk> it is thought to affect 2 million people in the UK, Ireland and across Northern Europe. Visit their website for more information on this condition and how to treat it.

If you want to help lift the winter blues, here are some things you can try in the home that may help.

- * To let in natural light it might seem obvious, but clean the windows!
- * Pull curtains back during the day and think twice about covering windows with net curtains.
- * If you have a sunny window,



the inside, perhaps next to the lock or handle

- Tell your carer, social worker, district nurse or any other relevant person what the container is and where it is
- Take this container with you every time you have an appointment with a health professional. This will provide them with a list of your medication

What if I need a new form?

You can get new forms from your community pharmacy or GP Practice.



turn it into a comfy reading corner with a luxurious chair and stack of books to encourage you to spend time there.

Lighten your decor with a spring colour palette. Choose warm and fresh colours with light woods, sparkly touches and fine textures, small patterns and prints. Select colours inspired by your spring garden, a pretty spring mixture of scarlet, coral, peach, daffodil yellow, emerald green, sky blue, cobalt blue and lilac should do the trick.

Jo Balston



Feature image: courtesy Designers Guild.

Drop In Clinics...



Many regional groups across the UK support a local 'drop-in' centre. This is usually held once a month where the lupus clinic is held (in this case Christchurch hospital) and is manned on a volunteer basis by lupus patients to give support and advice to others who require it. It is not for advice on treatments- that is the consultant and nurses roles, but for help and support for other aspects that concern the lupus patient.

If you have any views on this or would like to get involved please get in touch we would love to talk to you.

Tamsin@dorsetlupus.com



IN MEMORY... Patricia Vaughan

A small group of us attended Patricia's funeral on 4th February at Christchurch Priory. It was a touching service with a wonderful and appropriate eulogy delivered by her nephew Andrew and a good number of attendees (Patricia had so many friends and admirers).

We were able to learn a little more of the life story of this brave lady, who was 86 when she died peacefully on 18 January in the University College Hospital, London after her enforced stay there since late November. She had been born in Liverpool but had moved to London as a child and had been diagnosed with rheumatoid arthritis as a teenager, and later of course with SLE as well. She met her husband Victor whilst working in London and moved down to Dorset where Victor was in business in Ferndown. Victor and Patricia later separated but Patricia stayed living here in Dorset, and when Victor developed Parkinson's Disease Patricia moved back in with him to care for him for the rest of his life. After his death she moved from their home in Alderholt into Christchurch and it was after this, in the 90's, that we first got to know her as a member of Dorset Lupus Group.

We admired her courage and fortitude from the start. She clearly suffered severely both with her crippling arthritis and her lupus, and it was notable that she was under the care of the eminent and world-famous Professor David Isenberg and his team at UCL. It soon became clear to us that she was a surprisingly active and determined lady, always busy (when not in hospital) and with many friends from a variety of groups that she supported and from Christchurch Priory where she was a regular and devout member of the congregation. In

addition to our Dorset Lupus Group, she also belonged to the local Arthritis group, to the Parkinson's group she had had joined during her husband's illness and continued to support right up to her death, to the local branch of the U3A (University of the Third Age), and a disabled swimming club.

Most especially, she was a shining example of the philosophy of 'Living With Lupus' (as opposed to "coping with" or "suffering from" lupus) and being determined to lead a full and happy life with a positive outlook, whatever her severe medical problems threw at her! One memory we have is from the day that our Group organised a 'Go That Extra Mile' walk one October a few years ago to raise funds for Lupus UK. We decided on a walk across Holt Heath. Despite dreadful, rainy, autumn weather, Patricia was there and as someone gave her a supportive hand she made a sprightly leap across a stream on a particularly wet and muddy part of the walk. Another particular memory shared by many of us was the New Year Luncheon when she felt poorly at the lunch table and passed out for a while: after coming round she politely but firmly refused to be taken off to hospital by the ambulance that had duly been called and insisted instead that we all relax and join her in enjoying our desserts and the rest of the function! What a marvellous lady!

Sue Anderson, the daughter of a lifelong friend from London that Patricia had made in her twenties, and who helped organise the funeral, has been kind enough to share her own memories of Patricia:

"It is remarkable that Patricia was so determined and strong willed. Her physical disabilities were not going to affect her being active and being able to do the things she wanted to do, as the



saying goes "where there is a will there is a way" and that really does sum up Patricia's thinking.

She was mentally bright and cheerful through all the pain. I have many memories of her laughter. She was intelligent, strong minded and knew what she wanted right up to the end. All her life she was very independent and very well organised."

Donations in Patricia's memory are being collected for Professor Isenberg's Rheumatology Department at UCL and should be sent please to the undertakers:

Moody's Funeral Directors, 57-59 Old Milton Road, New Milton, Hants BH25 6DJ

Cheques to be made out to 'Rheumatology Discretionary Fund, UCL Charity'. Please be generous, this is a very worthy cause and Patricia was deeply indebted to all the help she was given by UCL. Professor Isenberg has been of course, and remains, a leading figure at the forefront of medical research into lupus around the world.

She will be remembered with admiration and affection by all of us who had the privilege to meet and get to know her a little. Her memory will live on amongst us and she will continue to be in our thoughts whenever we get together as a group.

New 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.



AGM

DorsetLupusGroup

**11am on Saturday May 11th
at Portfield Community
Hall, Portfield Road,
Chirstchurch.**

**Refreshments will be
available and Dr Neil
Hopkinson will be
speaking afterwards**

Spring time Recipes...



**Springtime
Spaghetti
& Meat-
balls**

With the warmer weather, take on this classic Italian recipe and replace the beef with pork and swap tomato sauce with garden greens.

Serves 4 Cook 20 mins Prep 15mins

INGREDIENTS

- 400g pork mince
- 1 small onion
- 4 garlic cloves, crushed
- Zest 1/2 lemon
- 50g grated parmesan cheese
- 1 tbsp olive oil
- 400g spaghetti
- 150ml double cream
- 200g fresh/ frozen peas
- Handful parsley, roughly chopped

METHOD

1. Mix mince, onion, garlic & zest with half the parmesan and some seasoning, shape into 16 walnut shaped balls. Heat the oil in a non-stick pan and fry the meatballs for 10-12 mins until golden.
2. Meanwhile, cook the pasta, drain and reserve 150ml of the cooking

liquid. Add the cream & 100ml pasta water to the meatballs, scraping the bottom of the pan to get all the sticky bits off. Bubble until thick and the meatballs are cooked through.

3. Add the peas, cook for a further 2 mins, then add the parsley. Stir through the pasta with a splash more pasta water to make the whole thing saucy. Sprinkle over remaining parmesan and serve.

Spring Salad Dressings

HERB & HORSERADISH DRESSING



A creamy dressing full of fresh herbs and tangy horseradish. Great with smoked fish or try a dollop on a

baked potato.

Makes 1/2 cup Prep: 20mins

INGREDIENTS

- 1/2 cup crème fraiche or reduced fat sour cream
- 1/3 cup finely chopped mixed fresh herbs, including chives, dill, flat-leaf parsley
- 2 tbsp prepared horse radish
- Pinch salt
- Freshly ground pepper to taste

METHOD

Whisk crème fraiche or sour cream, herbs, horse radish, salt and pepper in a small bowl until combined.

Cover and refrigerate for up to a week.

ORANGE-OREGANO DRESSING



What this dressing lacks in calories and fat it makes up for in big bold orange flavour and notes of oregano.

Makes 1 cup Prep: 10mins

INGREDIENTS

- 1/2 tspn orange zest, freshly grated
- 1/2 cup orange juice
- 1/4 cup cider vinegar
- 1 tbsp extra virgin olive oil
- 2 tspn fresh oregano chopped or 3/4 tspn dried
- 1 tspn Dijon mustard
- 1/2 tspn salt
- 1/2 tspn pepper

METHOD

Place all ingredients into a jar.

Cover and shake to combine

Cover and refrigerate for up to a week.

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?

The Annual Conference & AGM...

LUPUS UK Annual Conference & AGM 2013

The conference will be held at the *Crowne Plaza Hotel, Chester on Sunday May 12th 2013.*

The conference speakers are:

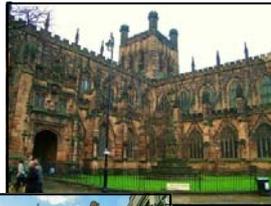
- Prof. Ian Bruce, *Professor of Rheumatology, Manchester*
- Elliot Bennett, *Lead BMS Autoimmunity, Lancs & Lakeland Immunology Service*
- Liz Hale, *Chartered Health Psychologist, Russells Hall Hospital, Dudley*

The subsidised fee of £15 includes tea/coffee on arrival, a delegate pack, day attendance at the Conference, hot/cold luncheon and

afternoon tea.

Meet and Greet

The host group hope you can call in to their welcoming event in the Malpas Suite, Crowne Plaza Chester Hotel, any time between 4.30 and 6.30pm on Saturday 11th May.



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

STAMPS COLLECTED
TO BEGINNING
APRIL...

5110



Dates for your Diary



May 10th 2013 World Lupus Day - stand at Bournemouth Hospital in main atrium 10-3pm

May 11th 2013 Dorset Group AGM at The Portfield Community Hall, Portfield Road, Christchurch at 11am

May 12th 2013 Conference in Chester

May 19th 2013 NGS at Manor Farm, Hampreston 1-5pm

June 9th 2013 NGS at Manor Farm, Hampreston 1-5pm

July 13th 2013 Bournemouth Pier coffee and walk 10.30am

July ?th 2013 Millbourne Port coffee and chat tbc

August 4th 2013 NGS at Manor Farm, Hampreston 1-5pm

Oct ? 2013 date tbc Walk the Extra Mile.

Nov ? 2013 date tbc Coffee and chat at Tarrant Monkton with Speaker

Your Committee...

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VACANT

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