

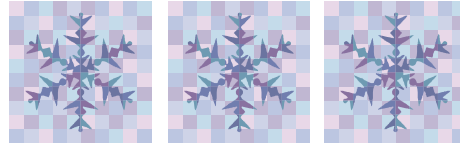


DORSET LUPUS GROUP NEWSLETTER

WINTER EDITION 2010

CHECK OUT OUR WEBSITE UPDATES

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



COMMITTEE MEMBERS

Chairperson & Treasurer:

Debbie Steel 01202 877390

debbie.steel@dorsetlupus.com

Vice-Chair: Chris McKenna

Secretary: Janet Bourne

Newsletter Editor: Tamsin
Campbelton 01202 470211

tamsin@dorsetlupus.com

Raffle & Events:

Carol Berkhauer

Librarians:

Yvonne & Guy Hosking

Other Members:

Yvonne & Charlie Bartlett

Gerrish Gray

Jean Durrant

Dawn Jeffs

Contacts: Tamsin

Campbelton 01202 470211

Gerrish Gray 01202 849144

Carole Frosdick (Lupus Nurse)

01202 705302 – please

leave contact details

and she will get back to you.

PATRONS

Christopher Chope OBE
MP and Christo Chope

SPONSORS

THE NIGHTJAR



CHAIRS COLUMN

Is it really nearly Christmas time again already? I swear those trees and decorations come out earlier each year! I hope all of you are enjoying the preparations for the holiday season and that the recent snowfall has not caused too many problems.

Looking back on 2010, the Group has had a busy and generally successful year. I would like to thank all the Committee, especially our new member, Jean Durrant. During the year we have had several events organised outside the Group – such as Skittles (by Mary & Leahn), a very wonderful Musical Evening (held by the Olive Branch Hand Bell Ringers and their musical friends), and an Easter Fayre (held by the Spetisbury Manor Residential Home). The Open Garden Afternoons continue to be great fun, as well as an excellent way to raise awareness about Lupus and the Group, whilst providing in-

valuable monies to fund research into the disease. Thank you to both Anne & Guy Trehane for their hospitality and all the others who have helped throughout the year.

Other new ventures this year include the Book Reviews, a revamp of our Website and a new Facebook page for Dorset Lupus – embracing modern technology, whilst still retaining contact by letter and telephone as well!

As for the future, well we have decided to rearrange the committee as follows: Tamsin has taken over full control of the Newsletter, and will also update our Facebook page.

Gerry will deal with the distribution of the Newsletter and regular updating of the website – to include updates and pictures after each event.

Jean and Tamsin will organise the Coffee Mornings and

they have many exciting ideas for speakers in the future

Janet is in charge of refreshments and will bring along the tea, coffee etc.

Smiley will be sending out all the Thank You's from us and has agreed to liaise with the Nightjar (who are still supporting us, albeit in a smaller capacity).

After much discussion we decided that in 2011 we shall concentrate on Coffee Mornings with or without speakers, and on the whole they will be held quarterly rather than monthly. I would, as always, welcome anyone's comments with regard to this. If anyone is interested in organising an event themselves, we would be happy to help, in any way possible, to make it a success.

On a final note I would like to remind everyone about the Lupus UK National Conference next May. It is being held in Southampton, so no excuses with it being so close. This year we are hoping to have the use of a mini bus – so if you are interested we can sort out a route to accommodate everyone who wants to come. They are always interesting and give a new perspective as to how others manage with their illness and what can be done to help.

I wish you all a very Merry Xmas and a Happy New

Year. *Debbie x*

EDITORS MESSAGE

I can't believe its nearly Xmas again and snowing at the end of November! As Debbie has mentioned I am now taking over the newsletter in its entirety mainly to relieve our extremely hard working Chair of some of the workload she has. I have had a little rejig of the newsletter and hope you like the new layout, and as

always any comments or suggestions are welcomed.

Please have a look at our new section on 'a different perspective' - I would love to hear from anyone who would like to tell their story.

In the meantime, have a wonderful Christmas and

New Year. *Tamsin x*

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 new volunteer and committee member, Jean, who is very approachable and getting involved with everything.

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 t remember what the Dr has said!

Please contact Debbie Steel 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.

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.

Help - DLG needs YOU!



I am including this again as we have had no responses (I am hopeful), please see if you can just spare a few hours to help us – we are all volunteers on the committee, so all time given is much appreciated.

The nature of Lupus means that we are not always fit enough to get involved with the Group on a regular basis. However, could you spare some time when we hold a fundraiser, or offer to go out and distribute leaflets, or make some cakes for a cake stall? Or attend a meeting, representing the Group occasionally?

We are trying to build up a team of members who may be able to help, from time to time, with many important roles. You may not want to get involved with the committee but with willing helpers from time to time, we could do so much more.

If you are interested, or would like to run your own fundraiser, then please call Debbie.



LEAFLETS



We have now got some new brightly coloured leaflets for the Dorset Lupus Group – describing a bit about Lupus and symptoms along with details of the committee and our group. If anyone would like a copy for themselves or to give out please get in touch with Debbie or Tamsin and we can arrange to distribute them to you.

Could you put some in your local Doctors Surgery, library, church or Information Office?

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

Trust Fund

The Dorset Lupus Group have a trust fund with just over £2,000 and would like to be able to use this money to help our members. It was originally donated by the Dorset Lions, from the proceeds of a half marathon, with the stipulation that it was to be used for local sufferers of lupus only.

We have had no applications for consideration in the last quarter.

If anyone would like to speak to Debbie confidentially, to see whether Dorset Lupus would be able to help, please call her on 01202 877390 or write to 7 Ebor Close, West Parley Ferndown, Dorset.

Strict confidentiality will be followed at all times.



A Review of Past Events

COFFEE MORNING SEPT 25TH

Manager, Christine Cooke, from the Christchurch branch of the Citizens Advice Bureau gave a very interesting talk on how and what the CAB are able to help with. If you would like to speak to CAB please call 01202 488442 to book an appointment.

CASTLEPOINT STAND OCT 9TH
BLANDFORD HOSPITAL OCT 11-15TH
B'MOUTH HOSPITAL OCT 13/14TH
POOLE HOSPITAL STAND OCT 19TH

Mixed success with all stands, the one at Castlepoint was a great success, the one in Blandford was unmanned so hard to tell and the Bournemouth Hospital one was last minute and the first time we have ever had a stand there which turned out to be a fantastic couple of days.

SHOE & BAG SALE OCT 22TH

The shoes-glorious-shoes event held at the communal hall in Rodhill, Puddletown raised the tidy sum of £200. It was, sorry to say a poorly attended event, but for the ladies that did come along to support Lupus on the night, it was an enjoyable evening. Thanks go to the ever faithful barman Christopher, I was told by many that he mixed a lovely Pimms!! A very brave soul as few men would get involved in a girly shoe, bag, boot & jewellery event. Thanks also to the lovely Maria Darling who brought her fantastic collection along for us to ooh & aah over & to try on, also Chris McKenna's sister Hilary and Aunty Ann, came all the way from Yorkshire to showcase her beautiful handmade jewellery in support of

Chris's Lupus event. Thanks to all who kindly donated goodies for the raffle & helped in any way, and also to the kind people who couldn't attend the event but sent generous donations, it's always very much appreciated.

ORCHARD AFTERNOON OCT 23RD

Despite heavy rain and howling winds, the afternoon went ahead without gazebos and was a good afternoon.

SPONSORED WALK OCT 31ST

A chilly yet invigorating walk, well attended and managed to raise lots of awareness - see later in newsletter.

SKITTLES NITE NOV 13TH

An entertaining evening and raised £60 which was donated to Frosty's Great South Run sponsorship.

Future Events



XMAS COFFEE MORNING AT THE HOWARD CENTRE, CHRISTCHURCH HOSP ON SAT 4TH DEC AT 10.30AM.

Come along and see us for the last get-together of the year. We have decided not to have a speaker as I'm sure there will be lots to catch up on and Christmassy talk to be had! There will be a Christmas theme along with lots of Christmas food and treats. There will be a chance to book your place at the New Year

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. The score so far stands at over 25,000.

meal in January at the Miramar Hotel as well as the last chance to buy your Lupus Christmas cards from Debbie. If anyone would like to donate a raffle prize can you kindly bring it along wrapped in Xmas paper. See you there!



NEW YEAR LUNCH
JANUARY 2011 - SUN
23RD JANUARY AT
12.30PM

We are now taking bookings for our Xmas lunch. This year was so successful at the Miramar Hotel in Bournemouth and thoroughly enjoyed by all that we have decided to hold the Xmas lunch there again. If you would like to book your place please call Tamsin on 01202 470211, £16.95 each for Lupus Group Members and £18.95 each for non-members. Places are booking up so don't delay!



WINTER COFFEE MORNING AT THE LANGTON ARMS, TARRANT MONKTON NR BLANDFORD FORUM ON SAT 26TH FEB-

RUARY 2011 AT 10.30AM.

Join us for our coffee and chat morning in Tarrant Monkton. Last time we were here it was very popular and we have a speaker on either 'holistic therapies' or 'nutrition and Lupus' planned. Come along and bring a friend!



AGM AT THE HOWARD CENTRE, CHRISTCHURCH HOSPITAL APRIL/ MAY

2011 TBC.

AND AFTER...



COFFEE MORNING AT THE HOWARD CENTRE, CHRISTCHURCH HOSPITAL APRIL/ MAY 2011 TBC. SPEAKER TBA



LUPUS UK ANNUAL CONFERENCE & AGM AT DE VERE HOTEL,

WEST QUAY ROAD, SOUTHAMPTON ON SUN 8TH MAY 2011



Recipe Corner

AVOCADO MELT

This can be served as a main course with a green salad or as a starter on a bed of watercress.

INGREDIENTS (for one person)

- * 1 Avocado per person (Use half an avocado for a starter)
- * 4 rashers streaky bacon (Use cooked prawns for an alternative)
- * 1 tablespoon salsa
- * 50g Good melting cheese (Cheddar, Stilton or Taleggio)
- * 2 tablespoons of double cream.

Pre heat grill

Cook bacon until crisp then snip into pieces (Prawns will already be cooked so leave this step out)

Put half the ingredients into half of the avocado in order of; salsa, bacon/prawns, cheese then cream.

Place on a grill pan and put on the lowest shelf. Grill until the top is brown and bubbling.

Delicious for lunch or dinner.

Thank you to Janet Bourne for emailing this to me - it sounds delicious and I will certainly be trying it!

What a great starter for Christmas!

Do you have a favorite recipe that you would like to share? Please email it to me on tamsin@dorsetlupus.com

Cat facts



On average, cats spend 2/3 of every day sleeping. That means a nine-year-old cat has been awake for only three years of its life!



A group of cats is called a 'clowder'.



A cat can jump up to 5 times its own height in a single bound.



A cat's nose pad is ridged with a unique pattern just like the fingerprint of a human.

Great South Run



WELL DONE to Frosty (Colette-above right) who ran

the GSR in October and raised a massive £1000 for the Dorset Lupus Group. Frosty's daughter Dani (above left) has Lupus. Next year it is intended for a group of 5 of her friends and family to run the Great South Run with her in aid of Lupus UK as she had so much fun doing it this year.

Go that eXtra mile



WELL DONE to members of the DLG who went that eXtra mile on the Halloween weekend. It was an enjoyable albeit chilly walk round with lots of awareness raised and balloons given out. Not all monies have been collected yet but we are aiming for about £600—a tremendous achievement.

COFFEE MORNINGS JUST GOT BETTER!

We are planning to bring in a speaker to our future coffee mornings and need your help for ideas – if you know anyone who would be willing to talk or would like a certain topic spoken on please contact Tamsin or Jean with details. The subject matter is open to anything and everything (within reason!), we want to arrange things that you want to listen to so have a think and let us know!



HeeHeeHee

I shall take you to bed and have my way with you.
 I will make you ache, shake and sweat until you moan and groan.
 I will make you beg for mercy, beg for me to stop.
 I will exhaust you to the point that you will be relieved when I'm finished with you.
 And, when I am finished, you will be weak for days.
 All my love, The Flu
 (Now, get your mind out of the gutter and go get your flu jab.)

The Pressure is on...



Donated to the Rheumatology Department Poole Hospital by The Dorset Lupus Group

Our Group recently approached the local hospitals to see if there was any equipment or items that we as a group could sponsor or donate. We heard back from Poole Hospital Rheumatology Dept asking if we could donate 3 blood pressure machines. These are for sole use of the Dept and we have had a plaque engraved. If anyone knows of any other local hospitals who could benefit from our help please get in touch with Debbie.

A Fathers Story...

It had been a strange Spring and early summer where we lived on the Isle of Man. Not because of the usual wet weather which dominates the climate in that northern isle, but because our daughter, Tamsin, had developed a series of seemingly unrelated illnesses following a trip to the Lake District where she had been walking in some exceptionally early and hot Spring sunshine.

It is difficult to recall all the conditions which she exhibited, although I distinctly remember something which resembled scabies and the onset of persistent and aching joint pains, particularly in her hands. On top of all that, her blood count remained unusually low and despite all attempts to diagnose the cause and influence its status, it continued to drop.

Of course, we had no way of knowing that these illnesses were related. Neither, it appeared, did our GP at a very highly regarded local practice. Each condition was treated individually but there seemed to be no let up at the onset of new challenges.

As time progressed, the aching limbs became more acute and then her hand joints began to swell. Rheumatoid arthritis was the main suspect and that, in particular, filled us with concern. She seemed so young to be heading down that route and we were keeping our fingers crossed that she would not be afflicted with that awful condition. And still, the blood counts continued to drop until, eventually, she was admitted to the island hospital for tests.

We still harboured the fear that she was, indeed, a victim of rheumatoid arthritis, so when eventually we were told to the contrary, we were, not surprisingly, greatly relieved. It didn't last long.

Apparently, the Isle of Man hospital was fortunate (and unusual) in having

a member of its medical staff who was familiar with what, to us, was an unheard of condition called lupus. That, they told us, was the cause of Tamsin's problems.

I remember communicating the information to a close family friend who had initially trained as a doctor before deciding on a career change. "Great news," I said. "It's not rheumatoid arthritis, just something called lupus."

He checked his medical dictionary that night and, quite diplomatically, called us back and asked if we had any idea what lupus was.

What he told us was both alarming and depressing, but even then, it did not seem like a complete disaster. The full realisation took time to sink in. We learned of its unique symptoms and its ability to mimic other illnesses.

How did we react? It was not the first time that our family had been affected by serious and incurable conditions, so were not completely without some basis for hope. The prognosis for lupus sufferers was, indeed, grim, but there was always the possibility of periods of remission and, particularly in females, the hope that eventually the condition might vanish.

As is so often the case with serious conditions, it can sometimes be almost worse for those who can only

look on and wish they could do something positive to help. That is not to diminish for one moment the affect on the sufferer, but it is a perspective which can be forgotten. Helplessness is one of the least attractive of all human emotions.

But I hope we did our best to be positive and to lend Tamsin the support we felt she needed.

The harsh fact, however, was that there was little we could do apart from lend support and advice. We were lucky. It was Tamsin's own resilience and determination not to let lupus destroy her life - particularly her rapidly approaching educational opportunities - which really had the greatest influence on us all. It is to her eternal credit that her resolve was total; God knows how she must have really been feeling and, at times, probably still does.

I know she has days and weeks when life is tough, but she seldom shows it apart from the accompanying tiredness. To all intents and purposes, it is often impossible to detect that she lives with such a threatening burden. And, perhaps, one day, she will be relieved of that burden because either her body will finally resist it or some, as yet, unknown cure will appear.

We can only hope. But then we have been doing that for a very long time.

Everyone has 'a different perspective'

Anyone that has been diagnosed or is in the process of being diagnosed with SLE or many of the related illnesses will find it difficult to accept and understand. In many cases it is hard not only for the sufferer but also for their family and friends. We would like to put in the next few issues of the newsletter, views from different family members and friends

and of course sufferers themselves. If you would like to write a piece (it doesn't have to be long) or have someone who could give their perspective on your illness, please email me at tamsin@dorsetlupus.com or call me if you would like to write something. Thank you to my dad Brian for writing the first piece on 'a different perspective'.

UCB/Immunomedic's Lupus Drug Excites Researchers



WORLD NEWS | NOVEMBER 12, 2010

Results from a Phase IIb study involving epratuzumab, a new humanised IgG1 monoclonal antibody in development by UCB and Immunomedics for systemic lupus erythematosus, have impressed investigators.

Data from the 12-week EMBLEM study were presented at the American College of Rheumatology meeting in Atlanta by lead investigator Daniel Wallace of Cedars-Sinai Medical Center and UCLA School of Medicine, Los Angeles. "This was primarily a dose-ranging study comparing five doses and dose schedules between 200mg and 3600mg against placebo," he told rheumatologists who crowded into an oral session to hear the data. But the study also suggested promising information on safety and efficacy from the 227 patients with active moderate and severe SLE who took part, he added.

All cumulative doses were superior to placebo, he said. "However, patients who received a cumulative dose of 2400mg either by 600mg weekly or 1200mg every other week saw a clear, clinically meaningful and statistically significant improvement in their condition by 12 weeks compared to placebo." Response rates observed for epratuzumab were more than double those for placebo. Improvement was measured by BILAG-2004 (British Isles Lupus Assessment Group) criteria and by SLEDAI (SLE Disease Activity Index) scores.

By week 12, significantly more patients receiving epratuzumab 600mg weekly had improved their baseline BILAG A/B scores to BILAG D in all six body systems (indicating no active disease) than patients receiving placebo.

Epratuzumab, which targets CD22,

also reduces B cells but only by a modest amount, said Dr Wallace. Benefit started to be apparent quickly, within four to eight weeks. This is faster-acting than drugs with a larger B-cell depleting effect, he commented.

"The degree of improvement was substantial. These were sick patients and I'm very excited about the results we saw from epratuzumab." Most patients had high disease activity at baseline, he noted, and over 70% had more than one BILAG A score across multiple organ systems.

Adverse events including infections and injection site reactions, and serious adverse events were similar in both the treatment and placebo arms of the study. "The drug was very well tolerated and there were no new safety signals," he added.

Co-investigator Ken Kalunion of the UCSD School of Medicine, La Jolla, said: "These are small numbers but the results are very encouraging. It's hard to say from a Phase II trial but this drug could prove to be a breakthrough in SLE". He added: "The most dramatic improvements seen were in the cardio respiratory and neuropsychiatric organ systems." In the former, all patients receiving the 600mg dose improved to BILAG D by 12 weeks. And in the neuropsychiatric system, 5 out of 6 patients in the 600mg weekly group went from BILAG B to D.

Another co-investigator, Vibeke Strand of Stanford University, Palo Alto, commented: "It is terrific to see improvement within three months that is clinically meaningful. I am very excited about epratuzumab. I think it's a great drug that may have potential to be an induction therapy. I'm eager to see where it goes in Phase III." Trials are expected to begin early 2011, Dr Wallace said.

SLE affects about 50 per 100,000 people in the USA and the condition is currently regarded as having an unmet clinical need. Although there are several symptomatic treatments there are none that tackle the underlying pathology of SLE.

To read more about this development go to the website of Brussels-based pharmaceutical company UCB at www.ucb.com and search their site for information on lupus and this new drug epratuzumab.

There seem to be promising developments on the medical research front for lupus on a frequent basis these days which really reinforces the value of our fundraising efforts to help Lupus UK make grants to support new research. Thanks go to all of you who support and help with those efforts.

Lupuzor Drug



Lupuzor™ This is a new drug that has been developed by ImmuPharma and licensed to Cephalon. If successful it seems that it will be the first drug ever specifically for lupus. According to the latest information found it is now in the final testing stages with the FDA (Federal Drug Administration) of America.

Link to northants information page is

http://www.northantslupusgroup.org.uk/LUPUZOR_1.html

The articles/reports that are shown on the Lupuzor™ pages were taken directly from the web sites of those they are attributed to. No responsibility is taken as to the accuracy of these or the suggested potential of Lupuzor™.

Adverts/ Wanted/ For Sale

Please let me know anything you would like to advertise, sell or maybe there is something that you are looking for, we have lots of members reading the newsletter who may be able to help.

Westbourne Osteopathic Clinic in Lymington. Experienced with auto immune diseases including SLE, Arthritis etc.

Please contact Oliver Curties *Bsc (Hons)Ost, Bsc(Hons)Nursing* for a consultation on 07957 309043

Freelance Architect available: Design, Planning and Building Regulations drawings. Are you considering an extension, conversion or new build? Please call for enquiries 07816 069566.

Gazebo available for hire (donation to Dorset Lupus Group!), new acquisition by DLG – do you need one for a garden event you're having? The gazebo is 3mx6m. Call Debbie for more information 01202 877390

Please email, call or text Tamsin on 07816 069566 to place an ad.

Every Penny Counts

For 2011 we have decided to step down organising so many events as they don't seem to have had the support of past years. In light of this we are sending out with all the winter newsletters a coin box and ask you to put it in your kitchen or hallway and over the year please put any spare change you have into the box. In sept/oct we will ask you to pay in all your collected monies to our bank account in time for Lupus Awareness Month. Please dig deep over the year and help us raise money for Lupus awareness.

If you require another box at some point in the year please let us know. Lets see who can collect the most money!



Dates for your Diary

Dec 4th - Xmas Coffee Morning, The Howard Centre, Christchurch at 10.30am

Jan 23rd 2011 - Xmas Lunch at The Miramar Hotel, Bournemouth at 12.30pm

Feb 26th 2011 - Coffee morning at the Langton Arms, Tarrant Monkton at 10.30am

April/ May 2011 - DLG AGM at The Howard Centre, Christchurch Hospital. Date and time tbc

April/ May 2011 - After AGM Coffee morning, at The Howard Centre, Christchurch Hospital. Date and time tbc

May 8th 2011 - Lupus UK Annual conference & AGM at The De Vere Hotel, West Quay Road, Southampton