



DORSET LUPUS GROUP NEWSLETTER

AUTUMN EDITION 2011

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COMMITTEE MEMBERS

Chairperson: Vacant

Vice-Chair: Jean Durrant
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Treasurer: Debbie Steel
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Secretary: Janet Bourne

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Gerrish Gray

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Jean Durrant 01258 860565
Debbie Steel 01202 877390
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
& Dr. Neil Hopkinson
DM FRCP

SPONSORS



CHAIRS COLUMN

Hello everyone

Welcome to yet another wonderful Newsletter. Thank you Tamsin for all your hard work – I appreciate just how much effort it takes to get everything together.

It is with a hint of sadness that I am writing to tell you all that I have resigned as Chairperson of the Group, with immediate effect. Having been an active member of the Committee since 2003/4 I find that there are other priorities in my life that I need to concentrate on at this time, and can therefore not spend sufficient time dealing with the group's affairs. I would like to thank all those

of you who have helped me over the years.

I shall continue to come along and get involved so you have not seen the last of me! I shall also remain as Treasurer, for the time being, so any donations should continue to come to me for banking and thanks. I am also a registered Contact so feel free to call me if I can help. I look forward to seeing you all at the Coffee Mornings when I will be free to sit and enjoy them without worrying about what is going on behind the scenes.....

Warm regards

Debbie x

A quick look...



Events

- Thankyou's
- Fastest Finger
- Book Review
- Chef Talk
- A Husband's Story
- Richards Skydive
- Dr H's Spot
- DEXA scans
- Short Story
- Hospital Car Share Service
- Donations
- Diary Dates!

EDITORS MESSAGE

Once again the nights are drawing in and Christmas is less than 100 days away!

We have a filled newsletter once again which I hope you will enjoy, along with some sad news that our Chair - Debbie Steel has decided to step down. We wish her well for the future and I'm sure will see her about at future events.

The sponsored walk at the start of September was a great success and although was organised late in the day quite a few turned out and it

was an enjoyable day.

Don't forget to buy your Xmas cards from us to save on postage from head office!

Start getting the layers out again and hope to see you at one of our autumn event!

Tamsin x



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!



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

Help - DLG Committee needs YOU!



I am including this again as we have had no responses (I am still 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.

We are also looking for a new committee members...if you have a few hours to spare or know someone who might like to join our committee (you don't have to have Lupus!) and help continue the wonderful job our present committee is doing, then please call Jean or Gerry.

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 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.

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?

A Review of Past Events

OKEFORD FITZPAINE OPEN GARDENS JULY 8TH & 9TH

Thanks to all who came—it was an exceptional two days and everyone was astounded by the gardens. Please see article on page 11.

MANOR FARM OPEN GARDEN JULY 31ST

Thank you to all the helpers and to everyone who came along. We had a fantastic afternoon and raised a huge £461.27. A very thoroughly enjoyable event. Thanks as always to the Trehanes for the use of their garden and for the donations from the refreshments.



Bottom pic - the Trehanes in their beautiful garden. Top pic - the girls enjoying themselves serving the teas!

SUMMER COFFEE MORNING & TALK BY DAVID HIGGINS AUGUST 6TH

A well attended morning with some lovely food to taste afterwards. Please see article on page 5.

WAREHAM BOAT TRIP SEPT 3RD

An enjoyable afternoon, smooth boat ride and thankfully the weather was very kind to us. Please see article on page 10.

Go that eXtra mile

Anyone who is planning an eXtra mile to support Lupus Awareness in October awareness month please let me know, send in your photos, events, anything you have done to help raise awareness please let us know about it!

Tick...Tock



Don't forget that the clocks change in October. Those dark nights will be drawing in soon.

SUNDAY 30th OCTOBER

Do you ever have a problem remembering which way the clocks go ...forwards or backwards.....

A little rhyme to help remember;

Spring ...Forwards

Fall (Autumn)..... Back

Future Events

AUTUMN COFFEE MORNING AT THE LANGTON ARMS, BLANDFORD ON SAT 12TH NOVEMBER AT 10.30AM



We have arranged a speaker - Chris Davies, who is a retired Physiotherapist. Please come along with your questions & queries as this will be a hands on session!



OCTOBER IS AWARENESS MONTH

Stands will be held at;

Christchurch Hospital 12th & 13th October in the main reception area—please come and say hello!

Bournemouth Hospital 19th October in the Atrium area.

CastlePoint Information Stand will be on the 29th October outside Marks & Spencers—please come along and show your support.



XMAS COFFEE MORNING - THE HOWARD CENTRE AT CHRISTCHURCH HOSPITAL. SAT 10TH DECEMBER AT 10.30AM.

Please bring along a friend and a wrapped xmas raffle prize. We will have an array of Christmas cards and goodies for sale as well as some lovely cakes and biscuits.



NEW YEAR LUNCH - ON SUNDAY 22ND JANUARY 2012 AT THE MIRAMAR HOTEL, BOURNEMOUTH AT NOON (12PM). THE

COST WILL BE £18 PER HEAD. PLEASE LET JEAN DURRANT KNOW IF YOU WOULD LIKE TO RESERVE A PLACE WITH AN £8 DEPOSIT PLEASE.



Please come along and support our events - the committee and members work hard to organise them.

TeeHeeHee...

Two peanuts walk into a really rough bar. Unfortunately one was a salted.

What does Dr Who eat with his pizza?.....Dalek Bread!

What do you call someone with jelly in one ear and custard in the other?.....A trifle deaf!

Why did the tomato blush?....Because it saw the salad dressing!

What is the best cheese to hide a horse?.....Mascarpone!

What cheese is made backwards? Edam!

Have you heard the one about the rhubarb who robbed a shop?.....He got taken into custardy!

Why did the basil & ginger get thrown in jail?...Because the lemon-grassed

A very HUGE Thank you..... and see you soon!

We would like to say a huge great big thank you to firstly our Chair - Debbie who has for personal, health and family reasons decided its time for her to step down, she will continue to be around until November and will continue to attend functions and help support the group. Debbie will be greatly missed from the committee and has been a great asset to us in the 7 years she has been actively involved.

Secondly to Chris McKenna - who stepped down from vice chair earlier this year and for Chris and her family's ongoing efforts to raise awareness for Lupus UK. I'm sure you will see her at a coffee morning in the future.

Also to Guy and Yvonne Hosking who have recently stepped down from the committee as Librarians but will continue to support and come along to local meetings and coffee mornings.

Fastest Finger in Dorset...



In our last newsletter there was an article about sun sense and SunSibility. The company have sent me some samples of sun screen, tinted moisturiser and waterproof suncream in handy little tubes great to slip into your handbag - the FIRST person who emails me we will send out the samples to! Hurry - there is only one bag going free!

SunSibility offer a wide range of UV protective clothing. For a free brochure phone 0202 224 2299 or online at www.sunsibility.co.uk (The SunSense collection are available on prescription).

Members of Lupus UK are offered 10% discount off the list prices.



And last but definitely not least Yvonne (Smiley) and Charlie Bartlett who have also decided to step down from the committee. Smiley will continue to do all the cards etc so please get in touch with her for those, and of course will be seen at meets and coffee mornings.

Thank you to all of you for all your help and dedication over the years and we hope to see you soon!

Clockwise from top - Smiley & Chas, Debbie, Guy & Yvonne, Chris McK.



Anti-Inflammatory Diet...

Not really a diet per se but actually an eating plan for life. Good for over-all health, can reduce heart disease risk, keep existing cardiac problems in check, reduce blood triglycerides and blood pressure, and soothe tender and stiff arthritic joints.

Experts concede that anti-inflammation eating is more effective for some health problems than others, however scientific evidence for disease reduction benefits of these eating plans is still being gathered.

Why anti-inflammatory diets?

An exact description of the anti-inflammatory diets varies depending on whom you ask. It is probably very close to the Mediterranean diet—that is fresh healthy food, smaller portions, healthy fats, olive oil, omega 3 fatty acids, more veg's less meat.

- * Eat plenty of fruit and veg.
- * Minimise saturated & hydrogenated fats.
- * Eat a good source of omega 3 fatty acids,

Bear named Cameron...

This handsome chappie was won by Jo Lines, a customer at Stafford



Hairdressers in Mudeford, Christchurch. Thanks to all the staff and customers there. Staffords will be doing another teddy raffle in December for Xmas!

Do you know any local businesses?

If anyone in the group is a regular customer of a local business—this could be; hairdressers, dentists, pharmacy etc... why not ask if they would like to do something similar. Anyone interested should contact Tamsin and she will arrange for a prize to raffle.

SEASONAL FLU REMINDER...

Get your jabs now!

such as fish or fish oil supplements & walnuts.

- * Watch your intake of refined carbohydrates (pasta and white rice).
- * Eat plenty of whole grains such as brown rice and bulgar wheat.
- * Eat lean protein sources such as chicken; cut back on red meat & full fat dairy foods.
- * Avoid refined & processed foods.
- * Spice it up - ginger, curry & other spices can have an anti-inflammatory effect.

The diet doesn't promise weight loss, but weight reduction does often occur, which makes sense given the makeup of the diet.

Not surprisingly, the A-I diet takes longer to work than an A-I medicine, more patience is needed and some people say they've noticed a difference in symptoms within just a few weeks.

Taken from Web MD - Healthy eating and diets. www.webmd.com/diet/guide/anti-inflammatory-diet-road-to-good-health

Book Review



'Coping with Lupus' by Robert H Phillips PhD

I often find it difficult to reach the end of books on SLE as they are too medical to engage my attention. However, this does not apply to 'Coping with Lupus' by Robert Phillips as it is written in straightforward English with sub-titles which allowed me to dip into the sections I was particularly interested in.

The first part of the book deals with the usual questions of what is lupus, how is it diagnosed and how is it treated. Because the book was written in 1991 there is no mention of

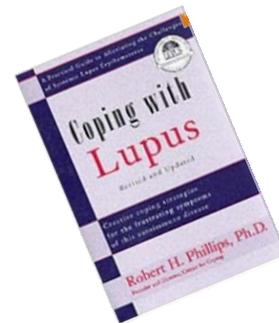
the new drug treatments coming on line, but it is, nonetheless, a very helpful summary of the disease.

The remainder of the book is dedicated to the psychological aspects of having lupus. It is in this section that the author, himself a practicing psychologist, covers all aspects of what it is like to have a chronic illness. He tackles the emotional implications on the patient and on the family, and issues such as depression, fear, and guilt. The author makes suggestions on how to cope with the necessary changes in lifestyle, and he also covers what it is like to live with someone who has lupus.

I found this common-sense book

very helpful and easy to follow and would strongly recommend to anyone who is finding it hard to come to terms with SLE.

On a practical matter – I do wish the book-binding was stronger as the book began to fall apart as I was reading it!



Reviewed by
Ann Mays

Chef talk...



Well, what can I say... the talk by Chef, David Higgins was very well received and I think I can say on behalf of everyone who attended that the session was a thoroughly enjoyable and informative morning. So much so, we were asking him back to do a repeat run (perhaps doing desserts this time...) before he had even left!

David had done a lot of research into Lupus and how people were affected in different ways and the different symptoms people suffered with, what foods we should steer clear of (namely the nightshades—bean sprouts, aubergines, mushrooms etc), and the talk was based around easy to use foods, easy to open items, ideas to make our lives in the kitchen easier as well as a cookery demonstration of two recipes - a risotto with bacon and a cous cous dish with prawns, which we were able to sample. Yummy!

David cooked and talked at the same time, taking us through easy ways of preparing vegetables, items of fresh and pantry foods that were easier to

use than others, giving us tips on stirring the risotto rice etc along the way. Both dishes he made look very simple to make and tasted delicious.

A booklet was handed out at the time to all who attended with useful tips on cooking and some recipes and recommended books and if anyone who didn't go would like a copy, please let Tamsin know and she can get one to you.

I have included three of the recipes from the booklet on page 5—the eggy bread one is particularly nice for a quick and easy lunch!



Some useful tips David left us with...

There are many frozen foods in the supermarkets and local shops that are in single portions ready to use, such as mashed potato, spinach, stir fry vegetables, fish—prawns, crab, mussels, cockles, smoked mackerel—chicken fillets, fresh herbs, cooked rice, sauté potatoes, frozen fruits, quorn.

There are also many chilled foods—small pieces of cheese, sold as a mixed bag or individually, food from the deli counter, fresh fish cut to size, pepperami.

Foods for the pantry—herbs in tubes, condensed milk in tubes, small tins of cooked minced beef in gravy or cooked chicken in white sauce, tins or foil pouches of tuna, quick cook rice in easy to cook bags, 2 minute microwave meals in pouches, baked beans and pasta in sauces in single microwave portion pots, cous cous, noodles, tofu.



We will be asking David to do another session—so for those who missed this one—be sure not to miss the next one.

Recipe Corner



COURGETTE & LEEK RISOTTO

Serves 2

INGREDIENTS

- * 1 small leek, thinly sliced
- * 1 courgette, thinly sliced
- * 150g Arborio risotto rice
- * 1 1/2 tbsp vegetable oil
- * 1 1/2 tbsp margarine/butter
- * 1 tsp mixed herbs
- * 1-2 garlic cloves, finely chopped
- * 600ml vegetable stock
- * 1tbsp grated Parmesan

METHOD

Heat the oil and half of the margarine/butter in a shallow pan and cook the leek, courgette and garlic for 3-4 minutes or until softened. Add the rice and stir well to coat it in the margarine/ butter and oil. Add the mixed herbs and season with salt and pepper.

Add 100ml of vegetable stock and simmer, stirring until it has been absorbed. Repeat adding a little stock at a time until the rice is tender and the liquid has all been absorbed. This will take about 25 minutes.

Mix in the Parmesan cheese and the

rest of the margarine/butter. Season to taste with salt and pepper and serve immediately.

Tip: I like to have a slice of garlic bread with risotto! You could even add bacon at the start to add a bit more flavour.

CHEESE & TOMATO EGGY BREAD

Serves 2

INGREDIENTS

- * 4 slices of bread
- * 2 eggs and a little milk
- * 4 oz grated cheese
- * one tomato sliced

METHOD

Take a slice of bread and dip it into the beaten egg and milk mixture.

Make sure its soaked in egg mixture and nice and absorbed. Put the grill on to preheat.

Nice put the slice into a very hot frying pan with a little oil or butter to stop it sticking.

Fry till lightly golden, then flip and do the same with the other side.

Your grill should be nice and hot now—add some grated cheese and a couple of tomato slices and grill until

the cheese has melted.

PRAWN COUS COUS

Serves 2

INGREDIENTS

- * 2 Shallots diced
- * 2 tspns olive oil
- * 1/2 courgette
- * 2 pinches turmeric
- * garlic to taste
- * ginger to taste
- * chilli to taste
- * 8 oz cous cous
- * 16 oz hot stock
- * 4 oz cooked prawns

METHOD

Sweat diced shallots and courgette in the olive oil, add the garlic, ginger and chilli, stir well.

Rain in the cous cous and sprinkle on the turmeric.

Pour on boiling stock, stir once, place a tight fitting lid on and leave to stand for 5 minutes.

Stir in cooked prawns and serve immediately.

ENJOY!

!VACANCY!

Our Chairperson Debbie Steel has decided for both, personal and health reasons to step down as our DLG Chair with immediate effect—she will be around to answer queries and wind down until November .

If you would be interested in the role of Chair, please get in touch asap. Lupus is not a requirement and we would like to hear from anyone who may be interested! please give Debbie a call on 01202 877390 to find out more or email debbie.steel@dorsetlupus.com.

!VACANCY!

Some of you may be aware that our lovely and very efficient Secretary Janet Bourne has decided for both personal and health reasons that she is going to step down as Group Secretary at the next AGM in April 2012. So.....we will soon have a vacancy on our committee! It is not too strenuous a post and you don't have to have lupus either! If you think you would be interested or know someone who might be please give Debbie a call on 01202 877390 debbie.steel@dorsetlupus.com who can tell you more about the role.

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.



A Husbands' Story...

By David Mays

The first time we noticed that Ann had a problem was after the birth of our second child in 1977. Her skin became covered in random lumps & bumps which came and went with no regularity which was disconcerting for Ann as we never knew when they would appear, leaving her feeling very down.

We started to involve the medical world who seemed mystified at what was happening, the basic conclusion being that the problem stemmed from an allergy to certain foods. This led to a series of tests & some interesting meal combinations for the rest of the family as Ann tried different recipes leaving out certain food groups.

The unsatisfactory element of all the tests was that no conclusion was ever reached. I spent a lot of time away from home through work which left Ann bringing the family up & feeling unwell most of the time. I guess I was not as sympathetic as I might have been but our lives were about to become even more complicated. We moved home 3 times, my job involved even more time away, the children were heading towards university & Ann's parents needed some help. There was still no resolution to

Ann's problems which were changing direction as the lumps were added to with random swellings of her lips, eyes & other areas which left her feeling more and more frustrated. The medical world were not making much progress & although GPs were trying various test it was frustrating for us as we did not know what was going on. We had access to private medical insurance which allowed us to try alternative medicine. Living near London at the time, we were able to find several 'alternative' clinics which meant a lot of travelling inside the M25. I have to admit to being sceptical about much of this and on occasions was only a reluctant chauffeur. Essentially I could not see how these would provide a definitive answer to find out what was wrong with Ann, who was always positive about these sessions. I remained slightly cynical but did my best to encourage her.

This carried on until 1999, the children had grown up & finished university, and I was asked to move to Geneva. Ann was not entirely happy about this but around the same time we had arranged to see Dr. David D'Cruz in London. I recall thinking "here we go again...", however after meeting him Ann was elated that he

had given her an answer to all the problems she had been experiencing over the years. Lupus. At least now we had something to work from. I had not heard of Lupus, had no idea what it was or where it came from or how to cure it, but after 22 years we finally had a diagnosis.

Whilst this was positive, it was a worry that there was no simple cure. It became clear that we would have to 'manage' the problem & we spent a fair bit of time travelling back & forth from Geneva to London. Ann was learning about Lupus all the time & sometimes I felt she got absorbed in the problem; but I suspect if it had been me, I would have been worse!

On our return to the UK & to Bournemouth, Ann had to find alternative methods of support. We went to London a few times but, from a practical point of view, Ann was a lot happier when she became aware of Dr Hopkinson & more importantly, the Dorset Lupus Support Group - knowing that there are people with similar problems trying to help each other out has been beneficial to her.

I still feel aggrieved there is no simple panacea, but I know Ann is more settled now & at the moment the best since 1977. Her Lupus is, I believe, relatively mild but has caused her anxieties which have not easily been resolved. I hope I have become more supportive over the years.

I realise that we will have to continue visiting doctors to keep Ann on a stable course. We have to put our family stresses into perspective against Lupus but I feel we are getting there with 'a little help from our friends!'

Frosty Runs again

Collete (right) will be running once again in this years Great South Run with two of her friends in October for the Dorset Lupus Group and hope to go above and beyond the £1000 raised last year. Collete's daughter Dani (left) has lupus.

If anyone would like to sponsor or go along to cheer her on please email Collette on frosty1808@aol.com.

Alternatively, Debbie has some sponsor forms which we will bring along to the coffee morning.



CHRISTMAS CARDS

Yes its that time again and we are all thinking about it.....

The Lupus UK Christmas cards will be out in September, please buy them directly from us at one of the meetings or coffee mornings and **save** on your postage costs!



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!

Richard's Skydive ...



Doctor H's Spot...

I lost a very dear friend Llywella Jones (Lly) to Lupus and MS back in March 2011. Although I knew Llywella was ill, I was shocked by the nature and cruelty that surrounds this disease. The combination of these two diseases - MS and Lupus together must have been truly horrible.

I never had the pleasure of meeting Lly, we were very close friends on Facebook though. In actual fact there were 4 of us; Lly, Nicky, Nadine and myself. Most evenings the four of us could be found chatting together and generally having a good old chin wag and making each other laugh. I only knew Lly for one year, and what a lovely person she was.

We were friends in every sense of the word, not a day goes past without her in our thoughts. She touched everyone she came in contact with.

I decided to do the Skydive for Lupus, because I had never heard of this disease until Lly told me about it last year. I had no idea how bad she was towards the end, I remember the night she told me, I asked her not to go into too much detail as I found it upsetting. I guess she knew from then on unless I asked that she wouldn't tell me. I was hoping she would be alive when it came to my jump on the 16th April but sadly she didn't make it, She died on March 12th.

Lly had everything planned and by that I mean, she knew she would be leaving this world...so we have somewhere to go where we can go to think about her. She was adamant that we were not to cry over a grave stone, so we have a special place that we can go to when we want to be near her, and one of her requests was that some of her ashes were scattered there. And we; we, are to say "nice boobs" every time we go, as her boobs have been scattered there.

The day of the Skydive came and I will be honest, I was very scared to say the least. We raised just over

£1000 with gift aid donations online...everyone dug deep which made it a little bit easier.

I had to wait an agonising 2 hours for the cloud to clear, and when it did all my fears went. I looked up to the sky and said to Lly that she would have to jump with me. I went up in the plane with 17 other jumpers, I was the only tandem jumper on that plane. To say they were winding me up would have been an understatement...I think that also helped gain confidence...after all, what could possibly go wrong!?

The time came at 15000 feet, 3 miles up....3 seconds and jump ...

WOW...

There are no words to describe the feeling jumping from a perfectly good aircraft at that altitude. The cloud level was probably 2 miles below and it looked incredible. The free fall lasted for 50 seconds and the noise was just incredible speeding towards the ground at 125 mph...then just as we entered the cloud and by which time I was struggling to breathe, the chute opened, a massive tug on the harness. Then complete silence, that's when I had to apologise for my language!!

We then did a series of very fast turns, my internal organs taking a beating followed by a very fast landing. Safe and sound!!

It was the proudest day of my life, we were all there that day...even Lly...I even made her jump with me!!

By Richard Brookes



Assessment of Osteoporosis risk

One of the challenges in treating lupus is assessment of complications which are not directly due to the disease itself. One such issue is the identification of those patients at risk of osteoporosis and importantly reducing their risk of fractures. Lupus patients may be more at risk of osteoporosis for a number of reasons, for example: they may have been on or continue on steroid medication; they are often females; and they may have mobility issues secondary to joint pain for example, etc.

A useful tool that can be used in the outpatient clinic is FRAX which stands for Fracture Risk assessment. This was developed at Sheffield University in collaboration with the World Health Organisation and is used in many parts of the world. It recognises the fact that Bone mineral density (as measured using a DEXA scanner for example) is not the only determinant of fracture risk. Other factors such as height, weight, smoking, alcohol (!), family history of fracture are also important. The FRAX tool can calculate the predicted risk of a hip fracture and other 'major' fractures (spine, wrist, shoulder, and hip) over the next 10 years. Based on this, a decision can be made of which patients should be recommended to have a DEXA scan (when not already available) and for whom treatment of their bone strength would be appropriate.

As many of you are aware although the treatment of osteoporosis can be very good, the drugs can have a number (often rare) of side-effects. The tool really allows an assessment of whether the advantages of treatment out-weigh the disadvantages.

I will talk about the various drugs we use for osteoporosis in a future communication.

Dr Neil Hopkinson

Dexa Scans...what you should expect

Taken from DEXA guidelines info sheet RB&CH

Having a DEXA scan - A Dual Energy X-ray Absorption (DEXA) or Bone Densitometry Scan, is designed to measure the bone mineral density within the skeleton. Unlike general x-ray examinations there are no pictures taken. The scan will pick up the amount of mineral salts you have in your bones and record them in a computer.

What happens when I have my scan? Before starting scans the radiographer will ask you to remove any metal objects (ie. Belts, zippers, buttons, hooks, clips) from around your waist area. There will be no need to change into a gown for this procedure unless the radiographer feels it is necessary due to a particular item of clothing. The radiographer will also measure your weight and height. These details will be entered onto the computer to allow the scanning to start. You will be asked to lie on your back on the scanning table. Three standard scans are performed on the lower spine and both hips—this is to obtain an average reading.

How long will it take? Your appointed time on the scanner is 15 minutes. However, each scan takes only approximately 30 seconds.

How will I get the results? The scan data is sent to your GP or Consultant, who will study the information and let you know the results at your next appointment.

Will it hurt? It is a painless procedure. Only the small vibrations given by the scanning motion, which have been

described as relaxing, are felt, and there are no after effects whatsoever.

Radiation survey The bone densitometer does use a small amount of x-rays to produce the information required. The dose of the scan is just ten percent of your normal everyday background radiation dose.

It is important for female patients to tell the radiographer if you are or think you might be pregnant.

DEXA Guidelines

Indications for DEXA bone density scanning and patients who require a DEXA scan, for whom the results are likely to change management of treatment:

- Oestrogen deficient women
- Men and women under 65 years on long term corticosteroid therapy
- Patients over 45 years who present with low trauma peripheral fractures
- Patients with x-ray appearance of osteopenia and/or end plate deformity suggesting osteoporosis
- Men and women with predisposing factors for secondary osteoporosis ie. Liver disease, alcoholism, malabsorption, thyroid disease,

hyperparathyroidism, RA, inflammatory bowel disease, hypogonadism in men.

- Family history of osteoporosis

DXA can be used to monitor response to treatment (but only after 3 years)

If people fulfil the guidelines GPs can request a DEXA scan directly through the department of radiology using an x-ray form.

Patients who do not need a DEXA scan; for whom a scan is not going to change their treatment management:

- Patients who have previously had a vertebral fragility fracture; they are at high risk of further fracture and should be treated
- Patients over the age of 65, starting steroids, who are likely to have therapy for at least 3 months; they are candidates for bone protection therapy at the time of starting the steroids
- Patients who have already had a hip fracture; by definition they are at high risk of future fractures and should be offered treatment
- Patients over 75 years; discuss before referral.

Freezer delivery...

After Margaret Hosking (Chair before Debbie) died many donations were given to us in her memory and we wanted to either put the money to something that would help a cause very dear to her heart or a memorial of some kind. After a very long time deliberating over what we felt was appropriate we asked Dr Hopkinson of Christchurch Lupus Clinic if there was anything we could contribute money towards that would help his clinic—his response...a freezer!



A freezer to keep blood samples in from patients to help with Lupus trials and research. We donated £600 for the purchase of the freezer along with a plaque which I am sure Margaret would be very pleased with.



Wareham Boat Cruise

What a lovely excursion! A dozen of us met up on Poole Quay on Saturday morning, 3rd September, to repeat the excursion that a number of us had done and enjoyed about 5 years ago – a trip on one of Greenslades' pleasure-cruise boats across the northern half of Poole Harbour, past all the various islands and up the River Frome to Wareham Quay (the trip includes a fascinating commentary about the islands, the oil wells and the surrounding countryside). The weather was really kind to us, warm, dry and calm (it had been a bit wet on the previous occasion, although it didn't spoil the day out) and most chose to sit on the top deck whilst a few stayed in the saloon below where we could sit and have a chat while still getting lovely views. On arrival at Wareham we had well over an hour ashore. There was a weekly market on the quay with some excellent stalls to browse, and most also dived into one or another of the quayside pubs with plenty of time to enjoy a tasty pub lunch. With the weather staying so nice most of us sat up on the top deck for the return trip to make the most of the views, the air, and the wonderfully smooth, gentle ride, and we docked back at Poole Quay by about half-past two. Everyone agreed that they had a lovely time and were clamouring for a repeat.



With autumn setting in soon with its uncertain, and possibly stormy, weather we had better make that a date for next year. There are some interesting excursions out of the harbour and over in the Swanage direction for us to pick from. One lands at Swanage and then takes the steam train on the Swanage Railway to Corfe Castle and another cruises along the Jurassic Coast past the cliffs and coves, with their wonderful rock formations, ledges, caves, and birdlife and maybe even spot the dolphin pod that lives out there. Probably no smugglers or dinosaurs these days though!

By Gerry Gray

Emotions of a Moment...

A short story by Dee Loughman

The salty water lapped rhythmically against the ancient boulders, worn smooth by time. A black crab the size of a fist scuttled toward a neighbour and out of sight. The wind blew in gentle gusts, warming the creature who stared into the distance and wrapping the hem of her dress around her ankles. The white cliffs across the water glistened and shone in glorious white of the reflected sunlight with just a hint of orange beginning to touch the horizon. A few spry clouds littered the sky and moved lazily by high above the shore. The fragile creature gazed over the sea, toward the mainland and the cliffs and the twenty or so approaching canoes, counting them. Trepidation and anticipation flooded her mind. All the world paused as she struggled to catch her breath, momentarily paralysed as every emotion battled to overwhelm her and take control.

This couldn't possibly be happening. Her father had told her stories of the warriors from across the water since she had been old enough to sit still for five minutes at a time. Tales of terror and heroism, strange rituals and dances. She had nightmares until her mother whispered in her ear a few days later- 'darling daughter, sleep easy for none will teach them the art of canoe building. The fishermen struggle to buy the canoes to fish from and none will teach them the art of preserving the wood from the seawater, despite the treasures and money offered or repercussions threatened. The workers cannot create enough canoes each year to replace the rotting ones, never mind build a fleet to cross the water with enough warriors to take our village'. The words spun through her mind, twisting and turning in a whirling dervish, attempting to convince her of their truth even now.

Oh she was tortured by the false sense of security the story had blanketed her vision with. Rage flooded her. Lies. Her fingernails pushed into the palms of her hands. How the hate of being lied to welled up and overflowed with frustration

and fury. Why had she believed?

It had been fifteen years since her mother had whispered words of comfort in a terrified child's ear and saved her from the nightmares that had haunted her. It had been a blessing, those years of feeling safe, but was it worth it for the current moment of terror.

There was nothing to do, nothing she could do now, or ever could have done to change either today's events or any events ever. She was an insignificant nothing in the scheme of things. There was no hope. She would be alone, murdered and her sacrifice would mean nothing.

But this was the only hope for her people. She must succeed. She must be brave. She must be a worthy sacrifice to prevent the hoard wiping her village out. Would the leader accept the marriage alliance, or the tribute or offers of a yearly tithe of food and boats. Could she negotiate a reprieve from the promised violence. Would her sisters survive the day or become slaves? She must try. She alone had been chosen. She was the only hope. A symbol of trust and friendship alone on the shore with wild flowers plaited through her hair and a crown on a cushion.

The echo of the oars touching into the water became audible and matched the beating of her heart. The inexorable approach of a hundred warriors continued. The fragile queen stood, alone, facing into the orange sunset, waiting. She would face the hoard, and hope to influence their leader and thus today's outcome and save her people from unnecessary bloodshed. Perhaps forge an alliance, perhaps offer a gift but mostly act as one person who could influence the lives of hundreds by one action, one moment of bravery. The moment approached and her knees trembled and the tribute weighed heavy in her hands.



Okeford Fitzpaine Open Gardens

David Hurron and myself would like to thank everyone who visited our gardens to help raise money for St. Andrews Church and Lupus Research on 8th and 9th July.

We raised a total of £1230 and was made up as follows:

£500 donated to St. Andrews Church

£500 donated to Lupus Research

£100 was raised by Anthea for Village Hall Funds

£30 donation received for Lupus Re search

£90.65 Total raised in Lupus Collection Tin and Plant Sales

£10 New member joined Dorset Lupus Group

We also wish to thank everyone who donated cakes, loaned us catering equipment, tables and places to park

cars. Especially those people who served the afternoon teas and did the washing up in Thelma's garden.

DPG & Lupus Group members, Thelma and Steve deserve special thanks. Thelma for the loan of her garden. Steve for printing all the posters and putting them all up in Okeford Fitzpaine and surrounding roads. Lupus and Dorset Perennial Group members who displayed the posters in towns and villages all over Dorset.

We received lots of well deserved compliments from visitors about the gardens and the teas. Visitors, who came from as far a field as Kent, Sussex and not to mention all over Dorset.

Your generous support was much appreciated. Well done !

With thanks and best wishes

Jean Durrant

Library Enquiries

Library Enquiries should now be directed to Gerrish Gray at

17 Minster View, Wimbourne, Dorset BH21 1BA.

01202 849144/ 07775524890 or gerrish.gray@dorsetlupus.com

DID YOU KNOW...

The 57 on Heinz ketchup bottles represents the number of varieties of pickles the company once had.

Every year about 98% of the atoms in your body are replaced.

Diet coke was only invented in 1982.

You burn more calories sleeping than you do watching tv.

The first product to have a bar code was Wrigleys Gum



Hospital Car Share Service

After a successful trial period, Poole Radio Cabs is pleased to announce the official launch of its new Hospital Car Share Service.

This service allows Car Share members discounted fares to and from Bournemouth and Christchurch Hospitals. Membership costs £5 per year and members receive significant discounts. It only takes one or two journeys for the scheme to pay for itself and many members are making significant savings on their transport costs.

The car share scheme now has over 2,500 members and continues to grow. The hospital car share service provides a fixed price hospital transport service where taxis are used as a convenient and cost effective alternative to buses and volunteer drivers. The service now includes an ambulance for sitting patients only, max 7 persons or max 3 wheelchairs.

The service covers Dorset, West Hampshire and South Wiltshire and provides transport to and from the Bournemouth and Christchurch Hospitals.

Benefits of the Scheme:

- You will be dropped off in the correct place - no long walks from the car parks
- You save up to 50% off regular taxi fares
- You don't have to worry about finding a parking space
- You can avoid traffic congestion by using taxi lanes
- You help to reduce pollution and traffic congestion by sharing your taxi.

Costs:

Its costs £5 to register as a car share

member (this is to cover administration costs and the cost of production of your car share ID card).

There after, journeys to Bournemouth and Christchurch Hospitals are charged at the following rates.

Zone	Distance	Single Fare	Return Fare
Zone 1	3 miles	£5.00	£10.00
Zone 2	6 miles	£7.00	£14.00
Zone 3	9 miles	£12.00	£24.00
Zone 4	14 miles	£16.00	£32.00
Zone 5	19 miles	£24.00	£48.00
Zone 6	24 miles	£27.50	£55.00
Zone 7	29 miles	£31.00	£62.00
Zone 8	30+ miles	Price on application	

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.

Puma Booster Electric Wheelchair please google 'puma powered wheelchair' for complete specification. This is in exceptional condition and has had minimal usage due to poor health. Must sell due to bereavement.

Cost £5,000 new but will accept £200. Please contact Valerie on 01202 624501

Dates for your Diary



Oct is Awareness Month -

Oct 12th & 13th Christchurch Hospital Stand in the main reception area

Oct 19th Bournemouth Hospital Stand in the atrium area

Oct 29th Castlepoint Information Stand - outside M&S

Nov 12th - Autumn Coffee Morning - Langton Arms, Blandford 10.30am

Dec 10th - Xmas Coffee Morning at The Howard Centre, Christchurch Hospital.

January 22nd 2012 - New Year Lunch at the Miramar Hotel at 12 noon.

Electric Bed 6 ft Adjustamatic electric bed, massage mattress & the bed can be automatically raised to accommodate linen change, personal care etc. Immaculate condition, hardly used. £500 or nearest offer. Please contact Ms Lawson on 01305 853379

Gazebo available for hire (donation to Dorset Lupus Group!), 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.

Its Collection Time!

For 2011 we decided not to organise so many events as they didn't seem to have had the support of past years. In the last Winter Newsletter we sent out a coin box and asked you to put it in your kitchen or hallway and over the year put any spare change you have into the box.

It is now time to count up those pennies and send in your collections!

Can you please send a cheque made out to the Dorset Lupus Group to Debbie Steel at 7 Ebor Close, West Parley, Ferndown, Dorset. BH22 8LZ.

Thank You!

Donations

Donations for June-August

- £60 Olive Branch Handbell Ringers
- £602.65 Jean & Davids Open Garden Event
- £50 Olive Branch Handbell Ringers
- £15.20 Joy Gallagher (change collected)
- £461.27 NGS Manor Farm Garden Refreshments
- £30 Jean (dog-sitting)
- £60 Teddy Bear Raffle (Cameron)
- £270 Waitrose at Parkstone
- £50 Anonymous donation for printing Newsletters

NGS Open Garden Refreshment amounts

23/05/11 £350.50

31/07/11 £461.27

Thank you

LUPUS FEST 2011 at

Kings Club, 6 Kings Street,
Weymouth, Dorset DT4 7EH

On fri 7th 20.00 - sun 9th Oct

Free entry.

Lupus Fest is an annual music-based charity intended to raise awareness of and research funds for the treatment of SLE and Anti-phospholipid/ Hughs Syndrome.

Email at
lupusfest@tiscali.co.uk or
website www.myspace.com/lupusfest

STOP PRESS

**BOOKING FORM FOR NEW YEAR LUNCH
AND ADDITIONAL MEETING INFORMATION**

NOVEMBER 12th - Coffee Morning at The Langton Arms, Tarrant Monkton, Nr. Blandford – 10.30 am – 12.30 am. Coffee and Danish available for purchase

Chris Davies (retired physio) will give us all a chance to discuss and chat about the importance of exercising and keeping us as mobile as possible, despite having Lupus.

Please remember that Lupus UK Christmas cards will be for sale at the meeting. All profits going towards Lupus Research.

BOOKING FORM

DORSET LUPUS GROUP NEW YEAR LUNCH ON -

SUNDAY 22nd JANUARY 2012 – 12 noon for 12.30 pm

at the MIRAMAR HOTEL, East Overcliffe Drive, Bournemouth BH1 3AL

We are once again returning to the Miramar Hotel for our New Year Lunch. A three course meal is available at a cost of £18 a head. Menu selections will be made on the day from their usual Sunday Lunch menu.

In order that we can give the hotel accurate numbers for the meal, we would be pleased if you could complete the booking slip below and return to me with a deposit of £8 a person, obviously this leaves an outstanding balance of £10 a head payable on the day. Thank you for your co-operation.

Could you please make the cheques payable to The Dorset Lupus Group and send them to: Jean Durrant, Acting Chairman, Dorset Lupus Group, Lime Tree Cottage, 20 Lower Street, Okeford Fitzpaine, Dorset DT11 ORN

BOOKING FORM - Please reserve me ____ places at the Dorset Lupus Group New Year Lunch on 22nd January 2012

NAME (s) _____

ADDRESS _____

_____ Tel: No. _____