

LUPUS UK

News & Views

SPRING 2015
NUMBER 105



Skin Camouflage Service
The Pain Toolkit - part one
The Importance of Footwear
Masterplans £4.1m research project
No Pain, All Gain



ISSN 1746-9910

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The National Magazine of **LUPUS UK**

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National Council meets in March and September and is comprised of the Officers/Trustees above together with the Chairpersons of Regional Groups or their representatives.

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THE LUPUS UK MEDICAL ADVISORY PANEL

LUPUS UK has appointed twelve prominent lupus specialists to advise on medical issues and on occasion to give expert opinion on grant applications which by their very nature are often scientific and complex. The twelve specialists cover a wide range of experience in lupus and allied conditions, and between them form an important part of the charity's strengths.

GROUPS AFFILIATED TO LUPUS UK

Caithness Lupus Support

Cover Photo - Courtesy of Paul Howard, Projects Officer.

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NEWS & VIEWS MAGAZINE

Published by: LUPUS UK, St James House, Eastern Road, Romford, Essex RM1 3NH

Email: christine@lupusuk.org.uk

Tel: 01708 731251

National Office: Chris Maker, Christine Watkins
Summer '15 Winter '15 Spring '16

Publication: 14 July 17 Nov 15 Mar

Articles due: 22 May 18 Sept 29 Jan

Please send your letters, photographs and other articles for possible publication to us at the above address. LUPUS UK has to reserve the right to edit or shorten articles and such decisions on publication must be final.

The articles appearing in 'LUPUS News & Views' do not necessarily reflect the opinions of LUPUS UK, its officers or members. Articles taken from local group newsletters are printed in News & Views with the consent of the author. Advertisements for products or services are not endorsed by LUPUS UK and persons diagnosed with lupus or suspecting the illness should always consult with their own physician to ensure proper evaluation and treatment.

From the Editorial Desk...

Spring is on its way with longer evenings and warmer weather, a good time to get active. In this edition of LUPUS UK News & Views we feature an article, pages 6 - 7, about pain management - the Pain Toolkit; the second part will feature in the summer edition of the magazine. The Pain Toolkit has been developed by Pete Moore, who spoke at last year's London Lupus Information Day, and who has lived with persistent pain for many years. We also feature an article 'No Pain No Gain' on page 26 - a series of simple exercises to improve fitness. We know that pain is a constant issue for many people who have lupus and taking up a moderate exercise regime will help maintain a level of mobility, flexibility and fitness.

Elsewhere in this edition we look at the importance of footwear and how to find the right shoes. On pages 8 - 9 Dr Anita Williams advises how to find the best footwear and what to look for in a good shoe, along with a great deal of other information. She and her research team are also interested in people's experiences of foot and footwear problems.

Changing Faces gave a presentation and demonstration at the London Lupus Information Day. Jon Williams, Head of UK Development, gives details of the Changing Faces Skin Camouflage Service and how it works on page 5. More information about the service can be obtained from Changing Faces. Their contact details may be found on page 40.

There is a great leap forward in medical research for people with lupus, specifically research into medication. A grant of over £4m has been made by the Medical Research Council for MASTERPLANS that will be more than matched by the pharmaceutical industry in kind. See page 11 for more information and how to get involved as a lupus patient.

Fundraising Focus highlights the wonderful work of our fundraisers helping to improve the lives of those with lupus. The photographs on pages 14, 16 - 17 bring their achievements to life!

Grand Draw 2015



Grand Draw tickets for 2015 are enclosed with your magazine. Please try and support us by selling as many tickets as possible. For additional supplies of tickets please telephone National Office on 01708 731251.

The first prize is £1,500, second prize £1,000, third prize £750, fourth prize £500 and fifth prize £250.



View from the Chair

As we begin a new year, I am really pleased to be able to share news with you of a research project into tailoring medication for lupus patients so that the consultants will have key information available to guide them. The scientists involved, led by Prof. Ian Bruce, have put in a bid for funding from the Medical Research Council and have been successful, after strong competition, in being awarded over £4million to cover the costs involved over the five years of the work.

Prof. Bruce has also raised well over double this amount (in kind - equipment, staff and advice) from a variety of other pharmaceutical sources. You can read much more about this on page 11. as well as find out how patients can get involved in various ways. Let me make it clear that this money is going direct to the scientists and institutions involved to cover the costs of staff, equipment, and the charity does not receive any of it, so we still need to continue our best efforts to bring in money for the valuable work which LUPUS UK does. So at last we have some really good news for lupus!

We still wait to hear from the National Institute for Health and Care Excellence (NICE) as to whether they will approve Belimumab being available on the NHS for lupus patients who have not seen any benefit from other medications, but by the time you read this, perhaps our patience

and persistence will have seen results.

As you are aware, the election takes place two days before our AGM and Information Day is held in Birmingham (see below). Health and the National Health Service is very high on the agenda, but it is too precious to be left just to the politicians! Commitment to its funding needs to be for the long-term rather than dependent on which political party is in power.

After some months of thought and planning, Simon Stevens, Chief Executive of the NHS has published his Five Year Forward View - you can read it on the NHS website. The voice of patients is recognised as needing to be heard and actively involved; it also contains details of how the service should be funded until 2020 and ways of improving the way it operates. On 1st April 64 Clinical Commissioning Groups, around the

country, will have more influence over the wider NHS budget and responsibility for providing services in their locality; the hope is that this will enable money to follow the patient to whichever part of the NHS is providing their care, whether it is GP, A&E or community services.

Have you got involved with your GP surgery's Patient Group? This is one way to make your voice heard in the provision of care for patients: although there may not be many lupus patients cared for by your GP surgery, many of the issues which we face are also experienced by most other patients with long term health conditions.

We are also always happy to hear from members and/or their families who have skills and experience who would like to help the charity carry forward its work.

Jane Dunnage

IMPORTANT INFORMATION



West Midlands LUPUS UK Lupus Information Day

Saturday 9th May 2015, The Studio, 7 Cannon Street, Birmingham, B2 5EP

Expert speakers on a variety of 'lupus' based subjects including -

**Prof Caroline Gordon, Consultant Rheumatologist,
City Hospital/University of Birmingham**

**Sarah Logan, Renal Specialist Nurse,
Queen Elizabeth Hospital, Birmingham**

**Dr Ben Rhodes, Consultant Rheumatologist,
Queen Elizabeth Hospital, Birmingham
(previously St Thomas')**

followed by a question and answer session

**This will be a ticketed event
(tickets will be free of charge)**

**For further details or to book a ticket please email:
info@lupusuk.org.uk**

or telephone Paul Howard on 01708 731251

Refreshments provided





Director's Report

The value of Specialist Lupus Nurses cannot be understated and you can read about the impact that one such nurse has made in Dorset on page 10. As previously advised funding was also agreed by the Trustees last year for a Specialist Lupus Nurse in Leicester where the recruitment process moves forward and we hope to advise of the appointment in the near future. As of the end of February a Specialist Lupus Nurse has been appointed in the West of Scotland. Karen Black will be working in NHS Lanarkshire and Glasgow Royal Infirmary.

With this edition of LUPUS UK News & Views you will receive a flyer for Go That Extra Mile. These have in the past been included with the summer edition but are sending them early this year as many of you have said that you would like to do your walks in the warmer weather. Planning your walk for 10th May would fit in nicely with World Lupus or alternatively you can hold a coffee morning, see page 35 for details. Your World Lupus Day poster and stickers are also enclosed. Tickets for the LUPUS UK Grand Draw 2015 are enclosed. These are a good way of raising lupus awareness as well as valued funding for the charity. We are grateful to all of you who buy or sell the draw tickets and if you require any more

please contact National Office.

The LUPUS UK Lupus Information Day programme continues with plans well advanced for the West Midlands LUPUS UK Lupus Information Day on Saturday 9th May in Birmingham. Tickets are free of charge but must be booked either online at info@lupusuk.org.uk or by telephone by contacting my colleague at National Office, Paul Howard. Plans are also underway for the Northern Ireland LUPUS UK Lupus Information Day on Saturday 17th October followed by Glasgow during May 2016.

The 24th LUPUS UK Annual General Meeting will be held on 9th May, prior to the West Midlands LUPUS UK Lupus Information Day and members will be receive their voting form along with the

Minutes of the 2014 AGM and accounts for 2014 by post.

Essex member Lorna Poole talks about her involvement with Healthwatch Havering on page 23. She explains the purpose of Healthwatch and how it helps patients particularly in the area of their rights and as she says if you can spare some time to get involved it would raise the profile of lupus and its treatment.

In the run up to the LUPUS UK AGM there will be a number of group meetings being held in the coming months and I will be making many visits and look forward to meeting as many of you as I possibly can as the days get longer and the weather gets warmer.

Chris Maker

GO THAT EXTRA MILE *for people with lupus!*

See flyer with this magazine

LUPUS UK GRANTS PROGRAMME 2015

Dr Neil Basu, University of Aberdeen	'Unravelling SLE Related Fatigue: Investigating the Role of mitochondrial Dysfunction in Skeletal muscle'	£35,052 over 18 months	With Trustees
Dr Hannah Cohen, UCLH, Department of Haematology	'Activated protein C resistance in patients with antiphospholipid antibodies: prevalence, association with anti-protein C antibodies, and severity of clinical phenotype'	£60,113 over 12 months	With Trustees
Professor Ian Bruce, University of Manchester/Manchester Royal Infirmary	'The Use of Novel Biological Therapies in the Treatment of Systemic Lupus Erythematosus (SLE): Extension for long-term follow up: British Isles Lupus Assessment Group Biologics Register (BILAG BR)'	£125,538 over 36 months	With Trustees
Dr Ahmed Zayat, University of Leeds/NIHR Leeds Musculoskeletal Biomedical Research Unit/Leeds Teaching Hospitals NHS Trust	'UltraSound Evaluation for musculoskeletal lupus (USEFUL)	£57,832 over 2 years	With Trustees



Treasurer's Report

The Management Accounts for the period ended 31st December 2014 currently show a surplus result of £23,045.55 against the budget. These figures are subject to amendment in order to produce the annual statutory accounts for the year.

INCOME at £890,972.08 was over budget of £780,000 by £110,972.08.

EXPENDITURE at £862,926.53 was over budget of £775,000 by £87,926.53.

GRANTS Our commitment to Grants and the amount paid out stood at £427,776 for the year under review, against the budget figure of £300,000 for the year. Our net committed grants for the years 2014 to 2019 now stand at £1,284,258.

OVERVIEW Income last year was again enhanced by legacies received of £114,000 and a donation of £51,500. Appeals Office was £20,000 ahead of budget as was National Office Appeals at £54,353.32 ahead of budget. However,

there are areas of shortfall, these being: Group Remittances, Member Subscriptions, Sales and National Draw. Interest & Dividends fell only marginally short of budget.

If Grants are taken out of the equation, expenditure was £39,849.47 within budget. Overall, expenditure was well controlled however, National Meetings was over budget due to venue, food and accommodation costs.

Our external investments stood at £237,620, a downturn of £2,636 over the twelve months to 31st December 2014. The market has been very mixed during 2014. Time will tell whether 2015 delivers

better results for the markets as a whole.

I am confident that we will maintain a position whereby our reserves will not only cover the Committed Grants outstanding, but also that of one year's costs of National Office required under our mandate. The position as at 31st December 2014 was that our reserves stood at £1,992,547.23 and our inclusive commitments £1,570,865.00.

Our Budget for 2015 indicates that an income of £800,000 is anticipated and our expenditure in the region of £767,000 thus giving an expected surplus for the year of £33,000.

Tina Stemp - Treasurer/Trustee

MANAGEMENT ACCOUNTS for the year to 31st December 2014

	BUDGET FOR YEAR	CUMULATIVE TO DATE	BUDGET TO DATE	OVER/UNDER TO DATE
INCOME	£	£	£	£
Member Subscriptions	65,000.00	60,191.50	65,000.00	-4,808.50
Group Remittances	100,000.00	90,756.75	100,000.00	-9,243.25
General Donations	137,000.00	193,414.63	137,000.00	56,414.63
Appeals Office	245,000.00	264,924.36	245,000.00	19,924.36
Appeals Office (Admin)	180,000.00	234,353.32	180,000.00	54,353.32
National Draw	13,000.00	12,014.00	13,000.00	-986.00
Sales	25,000.00	20,643.31	25,000.00	-4,356.69
Interest & Dividends	15,000.00	14,674.21	15,000.00	-325.79
Sundries	0.00	0.00	00.00	0.00
TOTAL INCOME	780,000.00	890,972.08	780,000.00	110,972.08
EXPENDITURE				
Grants	300,000.00	427,776.00	300,000.00	127,776.00
National Meetings	25,000.00	29,205.80	25,000.00	4,205.80
National Office	85,000.00	83,200.15	85,000.00	-1,799.85
Resale Items	20,000.00	10,050.97	20,000.00	-9,949.03
Publicity	27,000.00	22,875.28	27,000.00	-4,124.72
National Publications	47,000.00	41,062.20	47,000.00	-5,937.80
Special Projects	69,000.00	55,558.30	69,000.00	-13,441.70
Travel	5,000.00	4,396.95	5,000.00	-603.05
Salaries	190,000.00	182,348.45	190,000.00	-7,651.55
Sundries	7,000.00	6,452.43	7,000.00	-547.57
TOTAL EXPENDITURE	775,000.00	862,926.53	775,000.00	87,926.53
SURPLUS/(DEFICIT)	5,000.00	28,045.55	5,000.00	23,045.55

Changing Faces Skin Camouflage Service

by Jon Williams, Head of the UK Development

What is the Skin Camouflage Service and how does it work?

For someone living with scarring or a skin condition that affects their appearance and confidence, specialist camouflage products offer a way to cope. The service helps individuals to regain self-confidence and independence. Our trained practitioners select the best colour match for each person's skin tone. They then teach clients how to apply the camouflage creams to improve the appearance of the affected areas. These creams can provide effective waterproof cover for a wide number of skin conditions including birthmarks, Lupus, Psoriasis, Vitiligo and those that cause scarring.

There is no charge for the consultation. However, Changing Faces is a charity and the Skin Camouflage Service relies on donations from the public and some funding by the NHS. Costs vary around the country from £70 to £120 to provide each consultation so donations are always welcome to help us continue this and other services. The service is available to anyone who would like to learn how to camouflage a scar or skin condition and is suitable for men, women and children five and over and ethnicities.

After the initial consultation, clients are given an advice leaflet to take away with them to remind them of how the process works. It includes information about how to use a moisturiser, barrier cream, sunscreen or medical preparation, prior to applying camouflage cover. The products are available on NHS prescription and the practitioner gives the client a letter to take to their GP advising which products the client needs.

The practitioners are volunteers who are specially trained on a course accredited by the Royal College of Nursing. The Service offers over 5,000 appointments every year and is provided in over 130 clinics across the UK, many in NHS settings and some in community centres. To find out more about the Service visit www.changingfaces.org.uk/skin-camouflage

Some of the following quotes demonstrate how beneficial the service is:

"I don't use skin camouflage every day, but when I'm meeting someone for the first time it stops vitiligo being a distraction"

"I know the scarring won't go away but now I can just be myself again"

"When I look in the mirror without it, all I

see is redness. As soon as the make-up's on, I feel so confident and can just get on with my life" Service user with rosacea
"My volunteer was absolutely lovely, a pleasure to be around. Very helpful and patient and showed me great products and how to use them"

CHANGING FACES - ITS PURPOSE AND OTHER WORK

Over one million people in the UK have conditions, scarring or marks that affect the appearance of their face or body. Other people's reactions to their appearance can make their experience very difficult. They often face staring, intrusive questions, teasing, prejudice and discrimination. Everyday situations like walking down the street, making friends, using public transport and applying for jobs can be daunting and overwhelming.

"It wasn't being in hospital that scared me most. It was walking down the street afterwards. People stared at me, called me names or crossed over to avoid me. I could tell they were embarrassed but their reactions really upset me. I felt so lonely and it was easier not to go out." Quote from a Changing Faces supporter

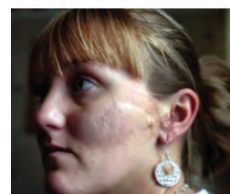
One of the most difficult problems someone with a disfigurement has to face is the assumptions people make about them. Three most common are:

- 1. People with an unusual appearance lead second rate lives – good looks are believed to be the key to success;**
- 2. People with disfigurements are 'different', 'abnormal' or as in horror films even 'scary' or 'nasty';**
- 3. People can, and should, get their condition 'fixed' by a surgeon.**

Such thinking and assumptions can have a negative impact on people's lives and lead to prejudice and discrimination. Changing Faces is the UK's leading charity supporting and representing people with disfigurement and enabling everyone, whether directly affected or not, to face disfigurement with confidence. The charity's work involves: Providing information, advice and support, to individuals, parents and teachers, both practical and emotional directly through our Changing Faces Practitioners or through a wide range of self-help resources. Offering staff training and consultancy for professionals and policy-makers to help create fair and inclusive environments. Campaigning for social change through promoting a society in which people are treated fairly and equally.

For more information visit:

www.changingfaces.org.uk





The Pain Toolkit and Self-Management in the Community (Part one)

by Peter Moore

At a recent presentation by Peter Moore, aimed at assisting clinicians in helping people to live with persistent pain, he presented his Pain Toolkit, a simple information booklet that provides handy tips and skills designed to support people living with the condition.

Peter has lived with persistent pain since the early 1990s, but in 1994 he successfully turned his life around and now presents to patient groups and healthcare practitioners in the UK and EU on the subject of managing persistent pain.

He is currently petitioning the government to encourage NHS Primary Care & Social Care to provide more pain self-management in all communities:

WELCOME TO THE PAIN TOOLKIT

For people who live with persistent pain

A persistent pain problem can be difficult to understand and manage on an everyday basis. This Pain Toolkit website has been developed from the Pain Toolkit, a simple information booklet that provides you with handy tips and skills to support you along the way to managing your pain.

It is not meant to be the last word in pain self-management but a handy guide to help you get started - all you need to be is willing to read and use it and take on board some of the suggestions.

"I didn't like that when I read it. Who was this Pete Moore telling me that I had to accept my pain? But when I sat down and thought it through, acceptance is the key to moving on and I now feel I have done that. By using some of the tools, I have got my family life back and even returned to work".

THESE TOOLS HAVE HELPED MANY PEOPLE AND COULD ALSO HELP YOU TOO!

Pete Moore, who has persistent pain, asthma and osteoarthritis, has put these tools together with the help of friends, family and health care professionals - special acknowledgement to Bradford Pain Rehabilitation Programme team & NHS Kirklees PCT.

TOOL ONE

Accept that you have persistent pain and then begin to move on

Acceptance is the first and the most important tool in your pain self-management toolkit.

Acceptance is not about giving up but recognising that you need to take more control with regards to how you can better self-manage your pain.

Acceptance is also a bit like opening a door - a door that will open to allow you in to lots of self-managing opportunities. The key that you need to open this door is not as large as you think. All you have to do is to be willing to use it and try and do things differently.

TOOL TWO

Get involved, start building a support team

Being successful in pain self-management means getting both help and support from others.



Ask your health care professional, friends, family and work colleagues about working more together - becoming a team.

Develop a pain self-management plan. Find out if there are other support groups in your community you could join which could provide you with more self-help management skills.

TOOL THREE

Pacing. Learn to pace yourself

Pacing daily activities is one of the key tools to self-managing your pain.

You need to begin to pace your work and also other everyday activities. Did you recognise yourself from the pain cycle? You tend to overdo things, or rest too much and become inactive and lose fitness. Pacing in short is: taking a break

before you need it throughout the day. But how can you remember to pace yourself?



Answer: One bite at a time! Pacing is carrying out activities one bite at a time and not tackling all of them at once! For examples of pacing daily activities and other useful resources, why not visit our resources page.

TOOL FOUR

Learn to prioritise and plan out your days

Prioritising and planning your days is an essential tool.

Make a list of things you would like to do but remember to be flexible. It is a great way to set yourself a starting point.

Examples

Monday AM - vacuum the living room and have a couple of breaks so that I pace myself.

Monday PM - prepare food for evening meal - sit down to do this.

Tuesday AM - go swimming, meet friend for a coffee/tea - practise some relaxation when I get home.

Tuesday PM - I write an activity plan for next day.

TOOL FIVE

Setting goals and action plans

Tuesday PM - I write an activity plan for next day.

So to avoid this happening set yourself, simple, realistic goals or action plans. Just as you need goal posts when playing



football, or a finishing line when racing - you need something to aim for.

Perhaps, you could set yourself a simple hourly, daily or weekly action plan. Always ask for help from your health care professional if you are not sure. You can also learn more about setting goals and action planning when you attend a self-management programme (SMP).



Self-Management Programmes (SMP)

These are run in the community by highly trained tutors who also have health conditions (including pain) themselves but have learned to become good self-managers. SMP's are run by Arthritis Care called Challenging Arthritis and the Expert Patients Programme.

TOOL SIX

Be patient with yourself

Take things steadily. It may take you a few weeks or months to see changes or improvements.

When you start to feel good, you may want to catch up with activities that you may have let go of. Don't be tempted to overdo it otherwise your chances of yet another setback could increase.

A good saying is 'take things one day at a time'. And also, ask for help and support from others - it's not a sign of weakness but a sign of strength.

Look out for part two of the Pain Toolkit in the summer edition of LUPUS UK News & Views.



Exercise Clinic now offered at The Barts Health Lupus Centre

The Barts Health Lupus Centre, located within Mile End Hospital, has one of the largest NHS cohorts of lupus patients in the UK with over 500 patients and is the largest regional centre in East London/Essex. The centre is run by a multi-disciplinary team of

healthcare professionals, including rheumatologists, renal physicians and specialist nurses who share a vision of improving the quality of life for lupus patients. The service has been assessed by NHS England as meeting its quality standards (clinical and governance), quality level 1, to be recognised as a specialist tertiary centre.

The department has in-depth experience of managing lupus in ethnic minorities and has a large cohort of Asian and Afro Caribbean patients (>400) who often have the most severe forms of lupus. These patients can have significant kidney problems, often without obvious symptoms, which can lead to long term damage if not picked up early. The Barts Centre has dedicated clinics run jointly with rheumatologists and renal physicians allowing early detection and early kidney biopsy to optimise management. The Centre has recently presented its experience of repeat kidney biopsies to tailor management of renal disease both at the American Society of Nephrology and American College of Rheumatology conferences in Nov 2014.

The Centre also now offers lupus patients unique access to an exercise clinic. Dr Dev Pyne, Clinical Lead for the Service, indicated that 'long term lupus patients have a significantly higher risk of heart disease and our data indicates that their overall physical activity levels are lower than in the general population. We know that aerobic exercise can markedly lower cardiovascular risk. We therefore felt it important to address patient fitness. We now offer a physiotherapy-led lupus exercise clinic, offering various exercise programs, with the aim of reducing long term heart disease. The patients receive baseline and post-program fitness testing, subsequent reassessment of cardiovascular risk parameters and group sessions on self management. The patients

are linked in with community health trainers for on-going sessions on physical activity, healthy eating, weight management and mental wellbeing with most sessions offered to them free'.

The Barts Centre is active in promoting research in lupus. The Centre has a close University collaboration with Queen Mary University, London, where laboratory research is undertaken investigating how genes predispose to lupus. The Centre is additionally involved in international multicentre clinical research trials investigating new treatments and also has a focus on ethnic differences in disease presentation and treatment responses. If you are interested in supporting Barts research Dr Pyne can be contacted via his PA at susan.lawrence@bartshealth.nhs.uk

Please Support World Lupus Day 10th May

See outside back cover



The Importance of Footwear - how to find the right shoes

Dr Anita Williams

Over a lifetime, our feet will walk the equivalent of five times around the world so it is important that we invest time in choosing the right shoes. We all have to wear shoes to protect our feet from the environment and it is crucial that they are the correct design, not just to accommodate our feet comfortably but for the activity that we are doing.

For people with conditions that affect the feet such as systemic lupus erythematosus, the right footwear is essential to insulate the feet from changes in temperature and extreme cold, maintaining function, resting symptomatic joints and preventing or limiting structural foot problems. The right footwear has a large role to play in the prevention and management of foot problems in the general population. However, when feet are affected with SLE there may be problems with circulation, such as Raynauds and/or problems with the way the joints of the feet work, which would certainly benefit from the right footwear.

However, getting the right footwear can be a challenge, not only finding the right shoes for comfort and protection but as footwear has a powerful influence on social and emotional aspects of our lives we like the shoes to meet our needs when it comes to social events.

HOW TO FIND THE BEST FOOTWEAR

There are many manufacturers of high street footwear that provide a variety of styles and widths which will accommodate the majority of feet and foot problems. It is difficult to recommend particular manufacturers and styles as all feet are different. These differences are not just in length but in the width of the forefoot, depth over the toes and the instep, arch height, flexibility of the joints, and angle of the toes to name just a few of the variations. Each manufacturer's designs will vary in relation to all these aspects and so matching the right feet to the right footwear can sometimes feel an onerous task.

HERE ARE A FEW TIPS TO HELP YOU -

- Do not rely on shoe size alone - it is the fit of the shoe and how you feel in the shoes that is more important - the size is just a guide.
- Try and find a shoe shop with a shoe fitter who can provide guidance as to the right design of shoe for your feet or an online shop with a free returns policy (The Healthy Footwear Guide contains a list of manufacturers

<http://www.healthy-footwear-guide.com/support.html>

- Feet tend to swell during the day, so buy shoes in the afternoon when your feet are at their largest.
- Make sure you try on both pairs of shoes as your feet may be a different size and width.
- Have your feet measured if they've become wider over the years, or have changed shape because of arthritis. Your feet may change shape when you stand up, so have them measured while standing.
- Make sure you try on shoes that have not been on display as these shoes will have been tried on frequently and may have stretched.
- Take your time and walk around the shop in the shoes. Even if they are comfortable in the shop make sure that you can return them for a full refund if you find that they are uncomfortable by wearing them for slightly longer at home (take care not to damage the soles on hard floors as they then cannot be returned).
- Don't be tempted to buy shoes in a 'sale' unless they fit perfectly and are comfortable.

WHAT TO LOOK FOR IN A GOOD SHOE

When you have joint problems and painful feet then comfort and support for your feet is a priority, particularly for high levels of activity such as shopping and walking distances. As a general rule it is desirable to reserve higher heels and strappy shoes for social occasions when you spend little time on your feet - these are what I call 'car to bar' shoes where they are essentially an adornment to your feet rather than something to walk in. If you are planning an important social event then you may benefit from resting your feet as much as possible before the event i.e. don't plan a long walk or shopping trip the same day so that your feet won't be as swollen and sore.

As far as your everyday shoes go, these

are important fitting points to look out for when choosing the right shoes:

Length - the general rule is that shoes should be long enough to have ½ inch or 1cm space between the longest toe and the end of the shoe

However, if you have a bunion and/or clawing of the toes you need to have shoes that are the length that your foot would be if all your toes are straight - this is so the widest part of your foot fits into the widest part of the shoe.

Width - the shoe should be wide enough so that the upper material is not pushed out of shape or forced to bulge over the side of the sole. There should be some 'give' in the upper over the forefoot but not so much that there is creasing. Make sure that the width at the heel is right. Some shoes that are wide enough at the front are too wide at the heel and may slip off.

Depth - the front of the shoe over the toes should be deep enough to accommodate any toes that may be clawed. There should be sufficient depth over the instep for you to easily get your foot inside the shoe. Alternatively a lace up shoe with more than three eyelets will open up sufficiently for you to get your feet into easily.

Size varies between shoe brands and style. Judge a shoe by how it feels on your foot and not just by the size marked on the shoe. Think about how the shoe fits around your toes, under the soles, and at the back of the heels.

Try shoes on with the type of socks or stockings you normally wear, or with any insoles or orthoses you normally wear with them. Some insoles may need extra depth, especially in the toe area.

If you are worried about the appearance of your feet, dark colours and a suede finish will help to disguise the problem.

These are important features to look out for when choosing the right everyday shoes:

It is best to choose shoes that are made from leather or a material that will conform to the shape of the foot. However, do not buy shoes if they require 'breaking in' and do not accept footwear if the sales person says that they will 'give'. The risk of this is

that they might cause damage to vulnerable areas of the foot. The shoe linings should be of leather or of material that will 'wick' away moisture.

The soles and heel should be of material that is firm enough to provide support to your feet and the shoe uppers but soft enough to provide good shock absorption and insulation - so avoid thin-soled shoes if you have circulatory problems.

The shoes should have a broad and stable heel with a height which doesn't put pressure on the ankle joint or the forefoot (the recommended heel height is no more than 4cm or 1.5 inches but the ideal heel height from one individual to the next will vary in relation to the structure and function of the foot and leg).

The shoe should have a fastening (either lace, strap or Velcro) which is needed to hold the foot in the back of the shoe to prevent slippage. The back of the shoe above the heel (heel counter) should be firm enough to support the rear of the foot but the top edge should not dig into the foot.

A cautionary note about slippers. Many people prefer to wear slippers in the house rather than shoes as they are often soft and comfortable for clawed toes and prominent joints. However, there are some negative aspects to wearing slippers, which you need to consider before choosing them as your 'house footwear':

Slippers aren't a good idea for those who have to wear special insoles or foot orthoses. They do not provide the additional support needed to ensure that the maximum benefits can be achieved from the insoles/foot orthoses

Slippers also sometimes contribute to falls in older people. The soles can lack

adequate cushioning and they can be generally unsupportive. Backless slippers and slippers with a high heel should not be worn as they are both unsafe and do not provide stability. Therefore, slippers should be reserved for foot protection and warmth whilst resting or for low levels of activity. The features of the ideal slipper are generally the same as for the ideal shoe.

If you are doing tasks within the home such as ironing or cooking which require standing for long periods then it is advisable that you wear your shoes rather than slippers particularly if you have been provided with special insoles or foot orthoses.

Slippers should be replaced as soon as the uppers, linings or soles start to wear out as in this state they can increase the risk of trips and falls and additionally can cause sore areas on the skin of the feet.

Shoes for special occasions (most of this section is for ladies but some of the tips are suitable for men who wish to wear more of a 'fashion' shoe for social occasions).

It is not recommended that high heels or court shoes are worn for everyday footwear, particularly if you need to wear foot orthoses. Foot orthoses generally don't fit into court shoes but it may be that the addition of a cushioning insole may be of some help in providing comfort.

However there may be occasions when this type of footwear can be used for periods of low level activity such as social events when you are sat down for most of the time.

The following are some tips for wearing higher heels or court shoes or 'fashion' shoe:

- Do not wear brand new shoes for a special event unless you have worn

them for short periods around the home over the duration of a few weeks

- Wear them for very short periods and always keep a pair of comfortable shoes handy in case you are desperate or to go home in
- Walk much slower and reduce your stride to reduce the impact on your feet
- Rest your feet before the important social event
- Often a shoe with a platform will offset the height of a heel and therefore reduce pressure on the forefoot i.e. a platform of 1cm will reduce the 'functional' overall height of a heel by 1cm.

Specialist / 'prescribed' footwear

Some people may have footwear prescribed especially for them by their consultant, GP or podiatrist. The shoes are usually provided by an orthotist who works in the orthotic services of NHS Trusts. You can also opt to see an orthotist or orthopaedic shoemaker privately. Each NHS hospital trust will have its own arrangements for footwear referral and entitlements. This footwear can be what is termed 'stock footwear' which is extra deep and wide or made to measure (bespoke) footwear made to a last specifically for your feet. Styles are often limited in comparison with retail footwear and you may wish to discuss options and look at the styles available before you decide whether you should be referred or not.

If you are unsure about any aspect of your footwear requirements then a Health Professions Council registered podiatrist will be able to provide advice on general retail footwear and foot orthoses and

should be able to direct you to an orthotist if you require prescribed, specialist footwear.

For a list of registered podiatrists contact the Society of Chiropractors and Podiatrists

Tel: 020 7234 8620

<http://www.feetforlife.org/>

Dr Anita Williams and a research team are interested in people's experiences of foot and footwear problems. If you are interested in filling in a questionnaire on this subject (and you haven't done so already) then please contact Anita on 0161 295 7027 or email a.e.williams1@salford.ac.uk



Delivering our Vision

Eight months ago the Rheumatology Department at Christchurch Hospital in Dorset appointed a lupus nurse specialist, Carol Brumpton - the first 12 months to be funded by LUPUS UK - and an additional consultant with an interest in lupus to join Dr Neil Hopkinson. Patients are already seeing the benefit and staff are realising the 'compassion in practice' vision.

The service now provides successful nurse-led clinics and an advice line. There are also growing links with colleagues throughout the county and the Wessex network. Special thanks are expressed to the Dorset Lupus Group for their support and encouragement throughout the year.

Dr Jonathan Marks, Consultant Rheumatologist, said: "Having a nurse specialist to complement our extended consultant team ensures more comprehensive care for our patients.

Carol has been a fantastic resource for patients and the department since joining the team. She has already helped lead improvements to the service, and her

commitment to provide a first class service for all of our lupus patients is evident."

The Rheumatology Department is now working to ensure the Trust's values and its vision to provide 'excellent care for every patient, every day, everywhere' is incorporated in its strategy, which also supports 'compassion in practice'.

Carol Brumpton, Lupus Specialist Nurse, explains: "Our aim is to help people stay independent and maximise their well-being. As a service we want to deliver a positive experience and high quality care for our patients. We can do this by strengthening our leadership, ensuring we have the right staff, with the right skills in

the right place."

Initial patient feedback also supports the improvements already made to the service with headlines such as:

- **100% of patients agreeing nurses were polite and courteous**
- **94% were less anxious about their condition following their hospital visit**
- **82% felt better able to cope with their condition**
- **100% were happy with the care they had received**
- **100% felt the lupus nurse specialist was a valuable addition to the team**



Tracy Hall, Directorate Manager Specialist Services

HOST A **lunch 4 lupus** EVENT THIS YEAR *see page 19*

Masterplans

by Prof. Ian Bruce and Jane Dunnage

Why doesn't my medication work better? Why is it so difficult to find the right treatment for lupus? Why do some people have to keep trying different treatments before the 'right one' works? Why don't the doctors find the right one straightaway?

Lupus is a complex and often unpredictable illness; the symptoms people present are very varied and can fluctuate, sometimes very suddenly. All of these things contribute to making a complex illness with a variety of causes, tricky for patients to live with and doctors to treat. Treatment sometimes feels like a lottery, and effective treatments still feel as if they are inaccessible.

The good news is that after very fierce competition, a grant of over £4million has been awarded by the Medical Research Council (MRC) to a team of scientists from around the UK, led by Professor Ian Bruce, for a large-scale research programme into lupus treatments. This study is called MASTERPLANS: Maximising the therapeutic Potential by Application of Novel and Stratified approaches and starts in summer 2015, lasting for five years.

The main centres involved are in Birmingham, Cambridge, Leeds, Bath and London (University College Hospital and Imperial College/Hammersmith hospital). All of the researchers have wide experience of treating lupus patients not just in rheumatology but also those with skin and kidney problems. Over £6million has been promised in cash or kind from companies who create treatments and diagnosis methods.

TELL ME MORE....

As you would expect, LUPUS UK is very excited about this news as it has great potential for lupus patients. We have already written a detailed letter of support to the MRC about how important this research will be for future research of

more effective treatments. The researchers have been keen to involve patients in a meaningful way, so Jane Dunnage has been asked to work on this as a co-collaborator with the research team, and has also been involved in the MRC interview.

The first part of the research will look into things which influence our medical make-up such as how proteins and metabolites work in our body and how our genes may be tweaked to perform better. The MASTERPLANS team will work to identify factors found in patients who respond well to a particular lupus treatment. Sample tissue, blood and urine from patients with skin or renal lupus will be used to identify biological predictors which could allow doctors to identify the treatment most likely to be effective on people with a similar profile.

Some of the drug companies have agreed to allow the MASTERPLANS researchers access to their research data from clinical trials into lupus medication. This is something which has rarely happened before and represents a big step forward in relations between the pharmaceutical industry, the medical/scientific community, and of course, patients. Recent advances in computer software have revolutionised access to information by greatly speeding up the analysis of material, making it possible for researchers to do much more detailed work and gain greater insights.

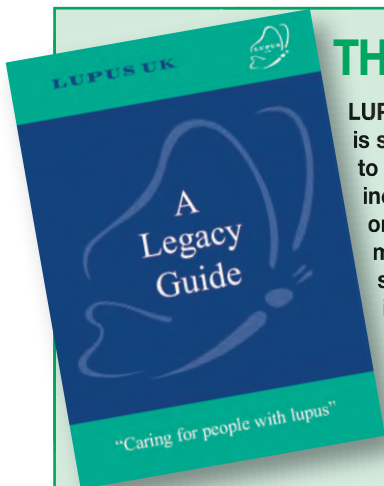
The second part of the research will use clinical trials in patients whose lupus affects either skin or kidney, to test whether this information can be used as proof of effectiveness.

WHAT DOES THIS MEAN TO PATIENTS?

As well as searching for lupus patients to take part in these trials, the researchers have also requested that lupus patients are allowed the opportunity to get involved in some aspects of the research early on as collaborators, to make the research as meaningful as possible. These patients should represent the lupus population by race, age and gender and have a variety of symptoms.

We are aiming to incorporate effective systems taking into account it's not easy to predict how well you will be on a certain date. There will be numerous ways to get involved, some will be via email and Skype, plus one-off events looking at issues such as use of patient's samples and data; others will be working on communication issues including use of appropriate language and the best way to inform patients, (again via the internet) with agreed deadlines for completion. There are opportunities for two patients or carers to be on various workstream panels; these will happen a couple of times a year and preferably need to be attended in person (or via Skype). There will be support to enable you to take part in the discussion.

If you are interested in knowing more about the research you can find more details on the LUPUS UK website or have an initial conversation with Jane Dunnage 020 8981 2766. Future editions of LUPUS UK News & Views will also carry more information.



THE LUPUS UK LEGACY GUIDE

LUPUS UK is seeking to increase income in order to make a stronger impact in funding essential research into lupus.

The Guide describes what is vital in the writing of a will and what can happen if people fail to record their wishes correctly. Almost 50% of adults have not made a will and their estates could thus be disposed of in a way that would not have met with their wishes.

The LUPUS UK Legacy Guide is comprehensive yet easily understood and is recommended to members of the charity. Contact National Office and we will send you a copy.

MEMBERSHIP SUBSCRIPTIONS 2015

LUPUS UK would like to thank members who have renewed their subscription for 2015, and would urge those yet to pay to PLEASE do so now by completing and returning the enclosed green form with your payment.

We send our appreciation for all donations added to subscriptions, and we hope that members understand that to contain costs we only write in thanks for donations over £20.

Fundraising Focus

We would like to thank ALL those who fundraise for us tirelessly and only space prevents us from listing everyone. This report shows funding £250 and over received between 1st September and 31st December 2014

Janine Hirsch, Fundraising Manager.



THE LUPUS UK FUNDRAISING GUIDE

If you are thinking of holding a fundraising event and would like a copy of this guide please contact National Office.

IMPORTANT INFORMATION If anyone puts forward a fundraiser for any of our events, can you please ensure that they will be able to raise the required sponsorship. In 2014 a number of fundraisers signed for events, and then did not raise the required sponsorship. We try to keep our pledges low, sometimes 50% lower than other charities, in the hope that the fundraisers will be able to reach their target. Unfortunately this has not always happened and some people only raise half the amount they have committed to raise, and on occasion cost the charity money.

DONATIONS RECEIVED AT NATIONAL OFFICE

	£		£		£
Richard Joseph Hanson, Legacy	37,000	Stewart Wiseman, BRIC Spartan Race	582	Molly Hilson, Langport Ladies Triathlon	346
Cecil Rosen Charitable Trust	8,000	Graeme McDermott,		Kaylee Fulton, 14" Haircut	344
Agnes Catherine Reid McNeil, Legacy	6,000	Great Scottish Half Marathon	560	Amy & Naomi Haslam, 4 Tough Mudders	342
Tom Carty, Butterfly Ball	5,200	Shona Turner, Great Scottish Run	560	Lynne Parlett, Great Scottish Swim	335
Chagar Superstore	4,500	Gerry Reilly, Skydive	550	All Saints Church, Woking	325
Gillian Forrest, Coffee Morning	2,376	Laura Doswell, Coffee Afternoon	520	Summer Flavin Big Fun Run	325
Kate Stewart, Donation	2,000	Aylesford Trust	500	Tim Prowse, Dawlish Marathon	322
Elsie Kennedy, Legacy	1,597	B-Looney Fundraising Event	500	Yvonne Reed, Charity Zip Slide	307
Brooke Weston Teaching School	1,593	Ipeco Holdings Ltd	500	Julie Thomason, Coffee & Cake Sale	300
Hugo Richards,		Mari McGregor, Great Scottish Run	500	Roger Vere Foundation	300
London to Edinburgh Walk	1,380	Lorna Souter, Tough Mudder	500	Jodie Davidson,	
Tom Levi Donation and		Emma Parker, Skydive	490	Junior Great Scottish Run	295
matched donation	1,200	Saeid Hakim-Azari,		Ovington Middle School	280
Sophie Beech, Great Yorkshire Run	1,176	Cardiff Half Marathon	450	Stripe Consulting donation	280
Brian O'Kane, Tough Mudder	1,051	Sam & Tom Dinwiddy,		Donna Todd, Aylsham 10k	280
Anne Harring, Legacy	1,050	Erewash Sprint Triathlon	448	Angela Beattie, Afternoon Tea	260
David Evans, Charity Bike Ride	1,045	Joseph James, Bradford Half Marathon	447	Katy Tidbury,	
Karl Parker, Tough Mudder	1,034	Pamela Gladstone, Cake & Candy Stall	435	Blenheim Palace Half Marathon	260
Adrian Piggott, Bide Ride	1,010	Josh Jenkinson, Virgin London Triathlon	430	Nigel Jeffries,	
James Beattie Trust	1,000	Ryan Hulme, Skydive	420	Vodafone Big Bold Challenge	256
Lorna Poole, Donation	1,000	Lauren Hill, Skydive	412	John M Archer Charitable Trust	250
Gary Randall, C2C Cycle Ride	995	Sophie Elliott, Great Yorkshire Run	410	Beauty Culture Salon, Fundraiser	250
Chelmsford Chargers, Ice Hockey Match	950	Lee Fotherington,		John Boland, Triathlon	250
Laura Sands, Amsterdam Marathon	938	Glasgow Half Marathon	408	Iris & John Davis, Legacy	250
Tom Jennings,		St. Julie's Catholic High School, Charity		Samantha Houston,	
Deloitte Ride Across Britain	880	Walk & Raffle	391	Body Shop Lucky Squares	250
Deborah Rae, Great Scottish Run	880	Robert Street, Sheffield Big Fun Run	390	Shaleen Jones, Hens & Chicks Night	250
Shelley McCormack, 3 Major Events	832	Michelle Bennett, Summer Concert	385	Clare Mayne, Autonomy	
Paul Penman,		Angela Beattie, Great Scottish Run	360	Ladies Wear Charity Cake Sale	250
Coast to Coast 198 mile walk	805	Kerry Robertson,		Right Choice Insurance Brokers,	
Safina Sher, Colour Me Rad 5k	783	Bupa Great Birmingham Run	358	Christmas Jumper Day	250
Holly Hodge, West Highland Way	683	Tina Chapman,		Tesco Helping Hand Donation	250
Deborah Redwood-Knight, Cardiff 10k	670	50th Birthday Celebrations	350	Emma Turner, Great North 10k	250
Lorna Soares, Super Juicing	660	Brogan & Aylee McGill,		Linda & William Walmsley,	
J Smart & Company	641	Great Scottish Run	350	Coffee Morning	250
Matt Smith/Adam Ross/Rosie Banks,		Mr & Mrs Moses,		James Wise Charitable Trust	250
Great Birmingham Run	622	Awareness Month Donations	350		
Adam Charlton, Sponsored Swim	607	Micky Gallacher, Coast to Coast Walk	347		

Regional Fundraising of £250 and over

NAME	REGION	EVENT	AMOUNT £
Wooler Walkers	NORTH EAST	Walk	3,027
Dungannon Leisure Centre	NORTHERN IRELAND	Felix 10k (2013/14)	1,500
Sir James Roll Charitable Trust	KENT	Donation	1,000
Ronald Cruikshanks Foundation	KENT	Donation	1,000
Yvonne Norton	WEST MIDLANDS	Raffle	934
Mary Hawkes	WESTERN	Quiz Night	801
Chrystal Golf Society	WEST MIDLANDS	Captain's Charity	780
North West Group	NORTH WEST	Fundraising Party	605
Tess Charlton	WESTERN	Birthday Party	600
Newry Bridge Club	NORTHERN IRELAND	Sponsor Evening	572
The Louis Marchesi Lodge	DEVON/CORNWALL	Masonic Donation	500
Mrs. M. Tate	NORTHERN IRELAND	Donation	500
Michael Wiggins	WEST MIDLANDS	Donation	500
Emma Mills	DEVON/CORNWALL	Fashion Show	460
Sarah Dunstan	DORSET	Table Top Sale	450
Pat Webber	WESTERN	Coffee Morning	441
Viv Howard	YORKSHIRE	Xmas Card Sales	427
Enfield Lupus Group	NORTH LONDON	Dance/Raffle	405
Catherine Mackenzie	NORTH EAST	Clothing Swap Party	403
Kath Evans	NORTH WEST	Afternoon Tea	381
Dave Evans	NORTH WEST	Warton/Coningsby Cycle Ride	374
Sue Dewerson	WEST MIDLANDS	Stamps etc.	326
Ray Wilson	NORTH WEST	Manchester/Blackpool Cycle Ride	326
Carol Barton	WEST MIDLANDS	Collecting Box	317
Edith & Robert Critchley	WEST MIDLANDS	Various	300
Iris Downey	WEST MIDLANDS	Table Top Sales	300
David Halhead	NORTH WEST	in lieu of Birthday gifts	265
Sheffield Support Group	YORKSHIRE	Fundraising	260
Janet Halhead	NORTH WEST	Open Farm Day	250
Great Midlands Fun Run	WEST MIDLANDS	Chosen Charity	250
Sue Conyers	NORTH WALES	Christmas Raffle	250

We would remind Groups and Fundraisers that if you are approaching National Companies to sponsor events or for donations, please contact Janine at National Office in the first instance as we wish to avoid duplicate requests which make us appear unprofessional.

GIFT AID

Many of you have already signed for Gift Aid but please ask anyone who is sending in a donation or completing a sponsor form to sign (providing of course they are a UK tax payer). Please ensure all those who sign for Gift Aid enter their **full name, home address and post code** as we are unable to make a claim if they are not complete or show a business address. Regional Groups can send all signed declarations here to National Office and we will process them.

For this period we have collected

£20,960.37.

DO YOU SHOP ONLINE?

Go to easyfundraising.org.uk, where money is donated to LUPUS UK every time you shop online and use one of the listed companies. This will not cost you any extra as these companies will pay us from their profits - it's a win/win situation. Just have a look at their website using this link

www.easyfundraising.org.uk

and shop to your hearts delight!

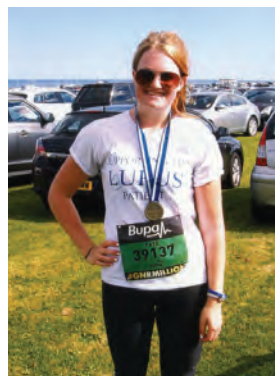
GIVE AS YOU EARN

Don't forget if your employer operates the Give as You Earn Scheme you can join and give to your favourite charity - just £1 per month will make a lot of difference.

For the period 1st September to 31st December 2014 we have collected **£2,582.**

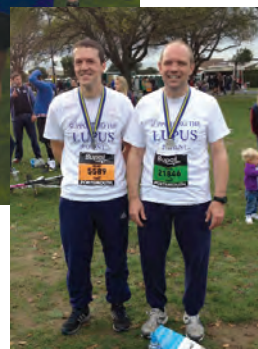
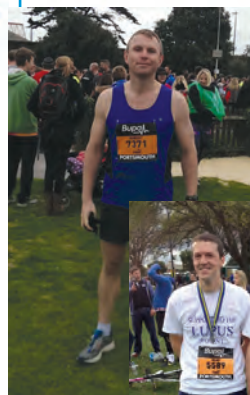
great north run

	£
Kerry Barrow	1,257
Mark Blanchfield	315
Angela Clarkson	900
Sophie Fawcett	370
Claire Gallagher	323
Caroline Kaye	2,761
Hannah Marshall	172
Dennis Millington	485
Gillian Sweeney	410
Faye Taylor	375
Amanda Thompson	410
Johnny Thompson	410
Shane Timmons	323



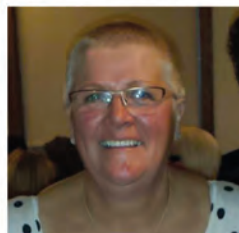
great south run

	£
Diana Anderson	415
David Barrell	102
Paul Blackmore	265
David Cottingham	470
Robert Duxbury	702
Richard Horrell	tba
George Penza	tba
Mark Phillips	326
Ilen Beyene Zewde	tba



Not all of the runners were Bond runners, as some had their own places and chose to run for LUPUS UK.

Hair Today Gone Tomorrow!



Karen McQuillan raised £4,567 and is splitting it between three charities. The Beatson, the west of Scotland cancer centre (she had cancer), MS (her daughter has it) and lupus (her friend's daughter has it). Karen raised this fantastic amount during the 2014 bowling season; she took a sponsor sheet to every competition that she entered between April and September. On the 19th October she held a charity night at her club (Hurlford BC) which featured a drag artist called Kitty Litter and all



monies raised from entry/bingo/raffle/sale of tablet/£1 coin throw at bottle all went into the pot. To top it all Karen then shaved off her hair.

Cake/Plant/Brooch/Earring and Card Sale



Sarah Dunstan, of the Dorset Group, and her parents held a cake/plant/brooch/earring and card sale in Parson's Passage in Cheap Street, Sherborne on Saturday 4th October. "We were overwhelmed by the contributions to the stall and by the number of people who came by to support us. We raised an amazing total of £450, and more importantly we were able to support a newly diagnosed lady and meet other local people who have or know someone with the illness. Thanks especially to Debbie and Dave for coming



up to support the event with literature and advice".

Cycle the 3 Cities for FREE!

If you have ever wanted to take part in an exciting challenge for charity here is your chance. We're looking for adventurous volunteers to cycle through three of Europe's most vibrant and well known cities! The challenge begins on the outskirts of London, then on to the continent where you'll cycle along the famous canals of Amsterdam before heading to the beautiful city of Brussels. For those of you in search of an exciting challenge just give us a call at the office on **01708 731251** or email - **janine@lupusuk.org.uk** with your home address and we will



send you a full information pack and everything you need to take part in this fantastic event.

An unforgettable experience awaits you.

Book via our website
www.lupusuk.org.uk

We have received donations in memory of the persons mentioned below and our sincere thanks and condolences go to their families and friends.

Christopher Adams, Enid Adlington, Mark 'Litlun' Allan, Michael Amos, Roy Antcliffe, Mrs. A. Beck, Ethel Bishop, Neeranauch Bloomfield, Keith Brown, Sheila Burgess, Mrs. M. Burns, Yvonne Buss, Barbara Butcher, Ellen Butcher, Eileen Carty, Sarah Charlton, Yvonne Clarke, Tracy Cleworth, Silvie Cohen, Margaret Cole, Shirley Collins, James Collinson, John Cook, Marjorie Dale, Edward Derbyshire, Pauline Dias, John Dunn, Barry Findlay, Harry Fisher, Paula Fitzsimmons, Lily May Gore, Amy Gorman, NESTA Greenfield, Win Gregory, Val Griffin, Eileen Haines, Amanda Hearty, Erina Herrick, Shirley Hilton, Sandra Illingworth, Linda Jane Ireland, Andrew Keane, Jayne Letch, Monica Maddocks, Hughie Malone, Mindy Matharu, Joan Matthews, Margaret McConochie, Barbara McDonald, Eve McKay, John Milligan, Stanley Moorey, Gladys Newstead, James Nock, Glenda Parry, Lea Patterson, Louise Rae, Judy Robbins, Gillian Robertson, Ian Savins, Patricia Sedgley, Helen Shirliff, Linda Skeet, Rose Smallwood, Bernard Smith, Mary & Alfred Tansley, Alan Tapping, Angela Taylor, Marion Taylor, David Teeder, Ashley Thompson, Cathy Tillett, Dorothy Tiley, Jayanthie Vikananda, Michelle Wardle, May Whitelock, Muriel Wickens, Ros Wiggins, Sarah Jean Yates

JUSTGIVING

We use JustGiving.com for on-line fundraising and donations. Visit www.justgiving.com/lupusuk. Instructions on how to donate/set up a sponsorship page are on this website and if you open a fundraising page please let Janine have the details. There is a "Donate now" button on the homepage of the LUPUS UK website www.lupusuk.org.uk which links directly to JustGiving.

For the period 1st September to 31st December 2014 we have collected **£64,237.72** via the JustGiving website. If you do give a donation through JustGiving please do not tick the "no further contact" box as your donation will then be sent to us anonymously and we cannot acknowledge receipt. We do not place anyone on our database unless they specifically ask to be included. All one off donations will receive an acknowledgement, but contact details will not be used for mailshot purposes, or passed to any third party. If you wish to make a one off payment to LUPUS UK it is more cost effective to send it direct to us as JustGiving do charge a commission and we cannot always identify the donation.

For the whole of 2014 we have collected £192,339.50 via Justgiving.



CHARITY FLOWERS DIRECT

You can order fresh flowers to be sent anywhere in the UK or Eire and all the profits will go to LUPUS UK, that means for every bouquet ordered at least 15% will go to benefit those with LUPUS.

Flowers are a wonderful gift for any occasion whether a birthday, anniversary, or just a "thank you" and you can benefit your charity at the same time.

Brochures are available from Janine at National Office or visit the website: www.charityflowers.co.uk
Tel: 08705 300 600 and quote LUPUS.

JustTextGiving™

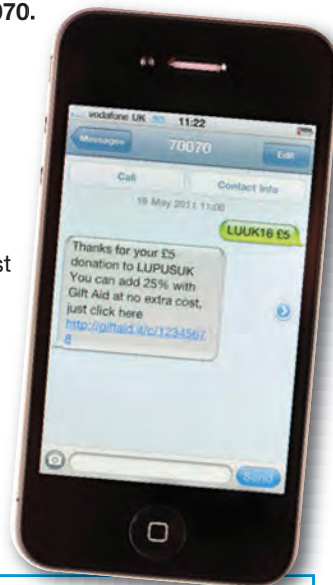
by **vodafone**

You can donate to LUPUS UK by text message - it's simple. Text LUUK16 and the amount you wish to donate to 70070 i.e. LUUK16 £10 to 70070.

All mobile operators will pass on 100% of the text donation to the charity via **JustTextGiving**.

Donors don't pay any extra fees and no deductions will be made from your text message free allowance or bundle. All it will cost you is the donation you make!

You must be over 16 and must be the bill payer or have the bill payer's permission. This is NOT a subscription service. For every message received you will receive one message back.



money giving

We also work with Virgin Money for online giving and donations via their website www.virginmoneygiving.com. You can set up your own fundraising page and ask your friends and family for sponsorship, or just send LUPUS UK a donation. For the period 1st September to 31st December 2014 we

have received £4,744.14 via Virgin Money Giving.

The total collected through the year via VirginMoney Giving is £31,161.87

Cycle from London to Paris for FREE!

If you have ever wanted to take part in an exhilarating challenge for charity here is your chance.

LUPUS UK are looking for adventurous volunteers to cycle from London to Paris connecting two of the worlds most chic cities on one of the best cycling routes in Europe! Cycling through

beautiful English villages and into stunning rural France you'll pass historical landmarks and famous battlefields from World

War I until you reach Paris, undoubtedly one of the most magical places on earth. The sense of achievement you'll experience will be one you'll treasure forever.

For those of you in search of the challenge of a lifetime simply give us a call at the office on **01708 731251** and we will send you a full information pack and everything you need to take part in this fantastic event, or register via our website:

www.lupusuk.org.uk

An unforgettable experience awaits you.



Some of our Wonderful Fundraisers



Karen Moody and Dance teacher Donna Curtis from West Sussex once again organised a BellyFunk Fusion Dance event entitled Tribe 2014 and raised £270 for LUPUS UK.



Claire Watts cake and coffee morning and matched giving by her partner, resulted in £200 being raised for LUPUS UK. Working as a nurse in Riyadh, Saudi Arabia and diagnosed with lupus two years ago, she is passionate about educating people about lupus and associated conditions. Fundraising isn't done in Saudi but the response was amazing.



Anthony Hawkins' mother-in-law Sue Bullock, who has lupus, cheered him on at the Stevenage Marathon in October.



Paul Penman and daughter Renay completed the Coast to Coast Walk for their chosen charities, officially 192 miles but they walked over 200 miles as accommodation was off route on a number occasions, raising awareness and over £700 for LUPUS UK.



Sophie Knight and her dad Steve completed the Great Birmingham Run (half marathon). They have raised £700 for LUPUS UK.



Donna Todd from Norfolk ran the Marriotts Way 10k in memory of her mum Barbara Butcher and raised £330.

Francisco Darka took part in a 10K run raising over £226.



Donna Fowler and family took part in the Victoria Park (London) Fun Run on 25th October.





Darren Wakeling took part in the Nuclear 8k fallout race in Brentwood, Essex. His partner, Nicola, has lupus. Darren's Ice Hockey Club also has connections with lupus and held a Charity Match in December which brought the total raised to a massive £1,550.

Rachel Wilmot, granddaughter of Hazel Wood, Regional co-ordinator Herts & Beds raised valuable funding inviting donations instead of gifts at her 21st.



Joe Kerry completed the Bradford Half Marathon to support his friend who has lupus and raised over £412 with a few more donations expected to roll in!



Linda Streeter from Kent held a Lunch4Lupus and with matched giving raised £1,000.



Graeme McDermott completed the Great Scottish Run, a half marathon in 2 hours, 3 minutes and 57 seconds and has raised over £600 for the charity. Next year he plans to take part in a Tough Mudder!

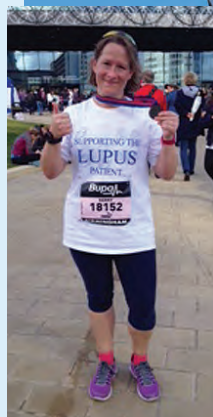


Gail and Darren Sykes took part in the Lisbon Marathon and raised £350.



Mitchell LeBaigue's skydive raised £995

Kathleen Winchester from Aberdeen hosted an Afternoon Tea during LAM with her husband as the waiter. Together the ladies raised £80 - thank you.



Kerry Robertson's lupus/kidney doctor delayed a kidney biopsy so she could take part in the BUPA Birmingham Half Marathon in October. Kerry completed the run and has so far raised over £375. Well done and thank you Kerry.

Sean Flynn, from Chorley, took part in the Mens Health Survival of the Fittest in Manchester on 8th November.



Our events organisers, Skyline held a fundraising day for LUPUS UK. Danielle Long who works there, is also running the London Marathon for us together with her mum Jackie.

Gerry Reilly completed a skydive and raised £550.



THE THRILL OF A LIFETIME AND RAISE MONEY FOR LUPUS UK!

WANTED!

Adventurous

people throughout the UK
to do something like this.....

for FREE!



Help us raise funds by making an exhilarating 10,000 feet freefall parachute jump. No experience is required and if you raise the minimum amount of sponsorship you will get to jump for FREE!

For a free information pack call
LUPUS UK
01708 731251

Events organised by SKYLINE Professional Events Organisers

STOP PRESS – if you would like to be involved in other exciting activities, i.e. three/four peaks challenge, coast to coast cycling, mountaineering, multi activity weekends and much more, a brochure is available from Outdoor Pursuits with something to suit everybody.

For details of any of these events, ring our
Fundraising Manager, Janine Hirsch on:

01708 731251

CAN YOU HELP?



Stamps 'n' All collecting for LUPUS UK

Susan Dewerson is collecting items on behalf of the charity and any of the following can be accepted:

Stamps and stamp collections – used or unused. If they are on envelopes or cards, leave about half a centimeter around the edges. Please don't peel stamps off – it reduces their value. If the stamps are on envelopes or cards postmarked before 1970 – DO NOT REMOVE THEM! This is because they can be worth more as a collectible item.

Envelopes and First-day covers - old, interesting looking, even with their letters in!

Postcards - with or without stamps on, please don't remove stamps.

Pre 1940s birthday cards and WW1 silk cards

Coins and bank notes - old or new, from anywhere in the world, obsolete or otherwise.

Precious metals and old keys - including broken jewellery, old trophies, gold, silver. If you have any old metal cutlery, this can also make money for LUPUS UK.

Watches, mobile phones, medals, badges.

Collection by arrangement

The minimum that can now be collected by arrangement, has been reduced from 15kg to 10kg. Just one phone call to Stamps n All 0845 2570813 - Monday to Wednesday and Friday and arrangements can be made for a collection up to five working days ahead at a day convenient to you. A time for collection cannot be specified. If you can provide a strong double walled cardboard box for shipping that would be a great help in keeping down costs. Remember all collections over 10kg arranged through Stamps n All are collected free of charge. Collections under 10kg have to be paid for by the sender.

Stamps etc can be mailed to:

Sue Dewerson, 86 Priory Ridge, Shrewsbury, Shropshire SY3 9EJ

Please ensure correct postage is added to any packages - thank you.

Call Sue on **07860 618016** or email **sue2149@tiscali.co.uk** if you require further information.

Collecting is going well and not many days go by without Sue receiving something through the post!!

PLEASE NOTE Diana Westrip no longer collects stamps on behalf of LUPUS UK. Sue Dewerson now collects Stamps 'n' All for the charity. When sending items would members please ensure the correct postage has been paid to avoid Sue having to bear the cost of insufficient postage and also the trip to the post office to collect the parcels.



Take a look in the loft. You would be amazed how much that old junk could raise for a good cause!

Getting Married?

We now provide 'Wedding Favours' for couples who wish to donate to LUPUS UK and have produced a folded table card, which can be personalised to the individual event. In some cases the couple have purchased the butterfly pins as well as making a donation, and then attached these to the cards.



The cards can be used for a number of different occasions and are not limited to weddings. If you would like further information please call National Office.



lunch4lupus is an event members can arrange anytime and is not restricted to Lupus Awareness Month. If you would like to host a ***lunch4lupus*** during the year, we'd be pleased to hear from you. The guests, instead of bringing a traditional party gift, are invited to make a donation to LUPUS UK.

The host will receive invites to send to their guests, together with donation forms and some helpful hints on hosting a successful event. If lunch isn't possible, members can host a coffee morning or a dinner party.

Just give National Office a call to request a lunch4lupus pack

Donate clothing with
CHARITY
ECOSYSTEM

Charity Ecosystem

The Charity Ecosystem is a fundraising partner, working with British charities who want to receive donations of clothing from their supporters but do not have the facilities to do this themselves.

Donations of clothing help charities raise money for their work and help you to clear your home of unwanted clothes. Charity Ecosystem will send you a bag to fill with your unwanted clothing. Only clothes in good condition are suitable for inclusion in Charity Ecosystem bags, so please don't include anything damaged, heavily worn or damp.

By signing into your Charity Ecosystem account, you can easily book a collection for any weekday you wish. A courier will collect the clothing from anywhere in the mainland UK. Please ensure the bag weighs at least 10kg, as this is the minimum weight that is eligible to be donated.

The Charity Ecosystem will make a £4.00 donation to your chosen charity for each bag received. They can also process Gift Aid claims on these donations, meaning an extra 25% is added to your donation at no cost to you.

Visit our Charity Ecosystem page to get started
<http://bit.ly/1vknFOj>

Trek to the summit of Kilimanjaro - FREE!

If you have ever wanted to undertake an exhilarating challenge for charity here is your chance. LUPUS UK are looking for adventurous volunteers to trek to the summit of the World's tallest free-standing mountain, and if you raise enough in sponsorship you will get to take part for free! Be prepared to immerse yourself in the tranquillity of the jungle, spectacular wildlife, breathtaking glaciers and experience something others will only ever dream of. For those of you with a sense of adventure and the desire to do something challenging for a great cause simply give us a call at the office on **01708 731251** and we will send you a full information pack and everything you need to take part in the experience of a lifetime.



Further information from LUPUS UK on 01708 731251 or visit our website where you can book online

Eclipse News

The Light Sensitivity Support Group

EU LEGISLATION ON EXEMPTIONS FOR INCANDESCENT LIGHTING

Sheila Gilmour MP (Edinburgh East) has been extremely supportive of SPECTRUM's campaign for people with light sensitive conditions to obtain incandescent lightbulbs. She raised this with the Parliamentary Under-Secretary of State for Energy and Climate Change (Amber Rudd) who replied:

'The European Commission has proposed changes to lighting regulation, including amendments to the definition of special purpose lights, but those have yet to be agreed. The Commission will be further reviewing lighting legislation, and we will continue to press for that review to take full account of any potential health implications of artificial lighting. That review is due to start in early 2015.'

There was a meeting between representatives of SPECTRUM Alliance and DECC (Dept. of Energy and Climate Change) on 8th October 2014. Although DECC officials acknowledged the problems of light sensitive sufferers, they appeared to focus on the difficulties of engaging with the EU and SPECTRUM representatives believe we still have a battle ahead in getting the verbal support translated into action.

LOW BLUE LIGHT PRODUCTS

The husband of an Eclipse member has found an interesting website www.lowbluelights.com.

This U.S. company markets products that naturally maximise melatonin, the so-called sleep hormone that is normally produced when you are in darkness. The use of artificial light before going to bed shuts down melatonin production because of the blue component in the lighting. This company produces glasses, lights and other products that filter out the blue spectrum and when used for one to three hours before retiring, help to improve sleep.

There are other health benefits of increasing melatonin production, including: improving mood control (also in bi-polar disorder and ADHD), reducing depression and preventing cancer or slowing down tumour growth.

LIGHTS

The following lights can be found in this range:

- 18 LED flexible arm backlight
- 7 watt 120v LED bulb
- LowBlue 3-LED Mini Spot

These LEDs do not emit any light in the UV or blue range which could be helpful to us. The spectral distribution charts do show a sharp high peak of intensity before 600nm (in the amber spectrum) and it is possible for some sufferers that a great intensity of light in any spectrum could cause problems, but this would need to be tested and it is certainly better than peaks in the blue spectrum found in most energy saving lighting.

NIGHT LIGHT

We were especially interested to see a night light in this range as it

is getting difficult to find the traditional tungsten variety that we use as a bathroom light in conjunction with a European adapter when we go away.

Conveniently for this purpose, this night light fixture has a standard European two-pin male plug. It produces light in the amber portion of the spectrum, well removed from the blue range.

Although it is recommended that we sleep in almost total darkness, this night light is a healthier option for those who need to get up or for children afraid of the dark.

GLASSES

The glasses block all light below 530 nm but thereafter do not admit a peak of light at any frequency, rather continuing more gradually to let light come through up to 700 nm (so intensity of light at any one frequency does not occur).

Filters for Phones and Computers

There are also filters for various phones, ipads, tablets and computers so potentially very helpful for Eclipse members.

If any member acquires one of these products, please let us know how you find it. Products can be purchased on the website www.lowbluelights.com.

LIGHTMARE.ORG

The co-ordinator of Lightmare.org (campaigning to end the use of blinding headlights) has sent a report of increased road accidents:

'According to a recent report by the Governors Highway Safety Assn., traffic related bicycle deaths are up 16% nationwide in the US, and 23% in California for the year 2012.

With constant technological improvements to cars and bikes as well as improved roadway lighting we should be seeing a drop in fatalities, not an increase. So what is driving this trend?

Common sense would say that when oncoming traffic is blinded by superbright headlights, when rear and sideview mirrors are flooded with light, when visual noise on the road is increased, then road users such as bicycle riders are at risk.'

This is another instance where the dazzling intensity of modern lighting is impacting on all, not merely those with light sensitive conditions.

FLEECE MASKS

Advertised in House of Bath catalogue:

- a pack of 2 Fleece Masks covering lower face and attached with ear elastics at £8.95
- Multi-wear Bandit Wrap Fleece at £7.95

These are intended to protect face from icy air but I found that no light was visible through mask so have used it for protection from light, along with wraparound protective glasses and a headscarf over top of head. Plus hat for extra coverage

Purchase from www.houseofbath.co.uk or Tel. 0871 984 2000

Radio 4 Book of the Week – March 2015

'Girl in the Dark' by Anna Lyndsey, published by Bloomsbury, is the autobiographical account of a person living with severe light sensitivity.

Chosen as the 'Book of the Week' for Radio 4 during the first

week of March, the Eclipse Support Group is mentioned in the book and information on our website has been used by Radio 4 for resource material. This should be good publicity to spread awareness.

Brenda Ryder

Eclipse Badges

We produce these badges with the aim of helping members to explain the nature of their condition and hopefully gain understanding from the strangers they encounter.

The two different badges are for those who only need to protect themselves from UV light, and thus can wear see-through masks, and those who have to cover up completely or at least avoid all bright light.

They are available from National Office at the cost of £2.50 each plus £1 for P&P (UK only).



Join us on Facebook 

Our Facebook page currently has over 14,240 'likes' and growing every day.

Facebook continues to be a fantastic way to share updates about LUPUS UK more regularly and with a wider audience. It has been very good for promoting events too. If anybody is holding an awareness or fundraising event that is open to the public, then we can share the details with all of our followers. By doing this we have already seen an increased interest in some events.

The Facebook page also acts as a forum and it can be a great place to discuss interesting topics with other people affected by lupus. In essence, Facebook has allowed LUPUS UK to get closer to our members. We can now share information more easily and we can bring people together for support in new ways. If you'd like to get involved with LUPUS UK on Facebook, then please go to:

www.facebook.com/LUPUSUK

You can also

Follow us on Twitter 

@LUPUSUK

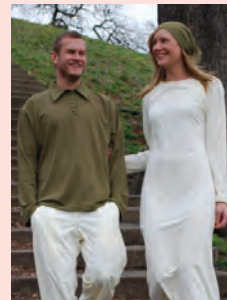


SunSibility - Stay Protected

SunSibility was set up purely to make going outdoors more achievable and primarily for those who do have a reaction, some of whom also helped in the initial design development.

Easy to wear designs and accessories can assist in achieving a better quality of life under UV rays. It is about finding what works for you:

- A SunSibility wide brim floppy hat or one of our new SPF 50 Wallaroo designs
- A handy wrap to keep in the car or in your bag
- A Sun Protective Umbrella and Made to Measure Gloves
- Detachable Collar and Sleeves so easy and light to wear and carry
- Drawstring Trousers rather than multiple sizes, buy one pair and if weight fluctuates due to steroids one pair will do...



This collection is for all, with fabulous men's and childrenswear designs - Sunsuits and sun creams are also available along with other innovative solutions to staying safe in the sun.

For further information visit **www.sunsibility.co.uk** or telephone **0208 224 2299** for a free brochure Quote News & Views to receive 10% off your first order.

easysearch
.org.uk

Easysearch is completely FREE and, by making just 10 searches a day, you could raise around £20.00 a year for LUPUS UK.

www.eclipse.lupusuk.org.uk



During November, Jane Robinson (Cambridge Lupus Group) took part in a two-day Patient Panel Meeting in Brussels along with representatives of other LUPUS EUROPE member countries. The Panel, led by Davide Mazzoni (Italy) who is a trained Patient Research Partner for LUPUS EUROPE (as reported in Winter 2014 News & Views), looked at several topics, including the use of Plaquenil, intravenous treatment, sunscreen etc. See *Jane's report below*.

With patients now being so much involved in research, "Patients' participation in research projects as partners" (lead author Davide Mazzoni) is now a published Letter-to-the-Editor of LUPUS, the international journal on lupus. "...With this letter the authors hope to open the debate about the role, opportunities and challenges of the involvement of lupus patients in research...."

The LUPUS EUROPE Annual Convention will run in tandem with the International Congress so reducing travel for delegates and costs for member countries attending. Yvonne and Peter Norton will represent LUPUS UK at EULAR (*European League Against Rheumatism*) and both the International Congress and LUPUS EUROPE Annual Convention.

Since World Lupus Day was established in 2004, there has been 'talk' regarding setting up a World Lupus Council, however, the stumbling blocks were always time and finance. The LFA (*Lupus Foundation of America*) has recently resurrected the idea with a proposal to form an International Lupus Federation with LFA and LUPUS UK as the leading members. An initial Meeting of representatives of several countries is planned for 9th April (*in London with LFA funding*) to discuss the organisation of the ILF (*International Lupus Federation*) and to establish an Executive Council who will have a one-day Meeting in Rome during June. The official launch of the ILF is planned for September in Vienna. Again, these arrangements will reduce travel and costs by taking place during EULAR and

the Vienna Congress. It has been agreed that Chris Maker and Yvonne Norton will attend the initial Meeting in London on behalf of LUPUS UK.

Yvonne Norton - UK Representative

IMPORTANT EVENTS ON THE HORIZON ARE:

World Lupus Day:

Worldwide - 10 May 2015

EULAR 2015:

Rome, Italy - 10 - 13 June 2015

The International Congress on Systemic Lupus Erythematosus:

Vienna, Austria - 2 - 6 September 2015

LUPUS EUROPE Annual Convention:

Vienna, Austria - 4 - 6 September 2015

LUPUS EUROPE PATIENT PANEL

BRUSSELS, BELGIUM

During November 2014, I was given the opportunity to attend a Patient Panel Meeting, organised by LUPUS EUROPE and funded by UCB (pharmaceutical company). The aim of the Panel was to discuss experiences related to treatment: including using Plaquenil, intravenous treatment, use of sunscreen, physical exercise, etc. to better understand the topic and design initiatives that will help treatment adherence and improve quality of life during treatment.

Travelling by Eurostar, I arrived in Brussels on the Saturday evening. Brussels is a great, small city and it was good to be there especially with some amazing Indian summer weather. I enjoyed a stroll around the city, some shopping and some people-watching whilst eating seafood (with chips and mayonnaise, of course).

The Meeting began on Sunday and, on arrival, delegates were greeted by our hosts from LUPUS Belgium (fr), Bernadette Van Leeuw and Alain Cornet. We all introduced ourselves and shared our lupus journeys along with hopes and concerns for the two days' work for which we had

signed up. The Panel was held in English which dealt with my concern of being an inept linguist! There were representatives there from Belgium, Denmark, Italy, The Netherlands, Spain and, of course, the UK. We found out more about the event and met representatives from UCB. We also discussed the types of treatments that we had experienced as lupus patients. After a group dinner we had a relatively early night, ready for the start of the Panel next day.

Monday morning, we heard about LUPUS EUROPE and its' goals and objectives to help set the scene for the work we were going to do. The first real session was where we discussed adherence to treatment including drugs, sunscreen etc. It was a good start as we each had stories of times we hadn't adhered to treatment for various reasons. We also heard from UCB representatives who presented work from a recent study. We split into small groups to discuss treatments and barriers to compliance of treatment regimens and potential solutions. The day ended with dinner in a traditional restaurant where mussels were their speciality and, despite some rain, there was a quick tour of

Brussels for those who wanted to see the sights by night.

On Tuesday morning, we had a visit from one of the prominent lupus specialists in Europe, Professor Houssiau. He was a great orator and answered questions about lupus, its treatment and future developments for treatment. We then worked in small groups to summarise actions and to look at making some key points, suggestions and recommendations for lupus patients, our healthcare professionals, our support organisations and the pharmaceutical industry. The session finished with us drafting letters to these organisations with our recommendations.

UCB had a team of people filming our testimonials through interviews when we spoke of our experience with lupus and how it had affected us. LUPUS EUROPE plans to use some of the video extracts to share our experience with other patients around Europe. This will be in the form of transcripts available on LUPUS EUROPE website or other media, as well as short videos on the website. UCB will also use the videos internally within the company, to help their researchers better understand

people living with lupus. It's always daunting for me when a camera is pointed in my face but the interviewer and filming crew were very professional and made it easier!

I met some lovely people during the Panel discussions and there was plenty of sharing of e-mail addresses and making

connections through Facebook and LinkedIn. It was a great opportunity to learn from others and to realise how lucky we are with the NHS in comparison to some of our European peers. I hope that the work we did over the two days has helped LUPUS EUROPE deliver its goals and objectives. It was also a great opportunity to tell the rest of Europe about

LUPUS UK and to look at ways of working together across Europe for the benefit of everyone who has lupus. The overwhelming feeling was that we could do more together collectively than we ever could as individual countries.

Jane Robinson
Cambridge Lupus Group

Clown Face and Hats

By Kate Gilbert

Member Kate Gilbert was fed up answering kind friends' enquiries and realising that they didn't know what lupus was, decided to make a small leaflet. They knew she had gone through a fair amount of hip surgery and therefore, since she wasn't getting better, she must not be doing the exercises properly! Also, wearing a hat indoors was thought peculiar, to say the least.

Kate handed the leaflet to her colleagues and friends and has had nothing but favourable responses and a lot of sympathy. Kate hopes others might also find it useful.



Clown Face and Hats

I have a condition called LUPUS.

It is a malfunction of the immune system which means that my body attacks itself in a number of ways.

It is obvious when my face goes spectacular!

Quite a lot of the time I am in pain which is sort of arthritic but there is no pattern to it. The medics have yet to get it under control. Exercise helps.

I am photophobic which means I have to stay out of the sun and I am allergic to some lights so I wear a hat and cover up my body.

A sub-condition means I have cold hands and feet so I sometimes wear gloves.

Another is dry eyes and mouth so I chew gum and look 'common'.

Sometimes I get very tired and have to rest.

There is no cure but it is under control.

***It is a help to get out and be with people so
THANK YOU FRIENDS.***

I hope this helps you to understand.

healthwatch

Your spotlight on health and social care services

Healthwatch was set up in 2012 in the wake of the Mid Staffordshire disaster to protect the interests of patients. There are 152 Healthwatches, answering to Healthwatch England, each of them an independent Private Limited Company. By law, those who plan and run health and social care services have to listen and respond to what the local Healthwatch has to say. They aim to develop new ways of engaging and informing people, especially those who sometimes struggle to be heard. They have the power to ask the health and social care regulator, the Care Quality Commission, to look at areas where they

have special concerns. Obviously problems vary in different parts of the country.

I never meant to join Healthwatch Havering, I only went to them to complain about a four week wait to see a GP, but when I said I had been a medical secretary, they said they needed my experience. I pointed out that I am over 80, with lupus and other disabilities, but I think they saw me as a typical problem patient. So I joined them and promptly got involved in the local row about the two hour wait for a blood test, then fell over once too often and had to test the resources of the Falls Clinic.

It is all very interesting, the Training Course is not very long but it drew my attention to a lot of patients' rights I had never considered. If you can spare a couple of days a month, sometimes only a few hours at a time, please consider joining. This is a great chance to get lupus and its treatment up to the front in your area; then write to LUPUS UK News and Views and let us all know how it works out!

**For more information go to
www.healthwatch.co.uk**

Lorna Poole, Essex Member

A Different Approach

David Hopkins, a lupus husband and carer

Though I don't have lupus, I have 'lived' with lupus for 25 years, seeing its effects on my wife, Mayne. My involvement over the last eight or nine years with my local lupus group has brought me into contact with many who suffer from this condition. So my comments are based on experience and observation.

It seems to me that the 'mainstream' treatment route has mixed levels of success. Most I have spoken to have indicated that whilst their medication regime may produce 'damage limitation' as regards symptoms, improvement is seldom achieved and 'side effects' can be major areas of concern. LUPUS UK is, for me, an organisation that informs without judgement and allows members to share experiences, good and bad, so I am using our magazine to share experience outside that 'mainstream' area. You can describe it as 'complementary' or 'alternative;' all I know is that I have spoken to members who have gained help in varying degrees from a range of treatments including acupuncture, homoeopathy, herbal remedies, supplements, chiropractic, diet, massage and numerous other therapies and treatments that might not find favour with the 'orthodox' medical world.

My wife's background included nursing but mainly revolved around complementary therapies. This has been of considerable assistance to her in dealing with her own lupus. The onset of a 'flare' on a Friday night can often be limited by inserting some needles in acupuncture points rather than waiting until the Monday when (possibly!) she might get to see a doctor. In the past three years she has made a very conscious effort to work on improving, not just limiting, her condition. Always an advocate of homoeopathy, she became aware of a particular homoeopath living over 100 miles from us, in Dorset. In late 2011, she began seeing him. He was a GP who had started investigating a range of treatments when he found that there were numerous conditions on which his prescription pad had little or no effect. His vigorous testing led him to conclude that indeed 'there are more things in heaven and earth than are dreamt of in (his old) philosophy.'

Those who question the concept of homoeopathic remedies having any effect as they are so 'diluted' might like to review recent studies on cellular memory, in particular in relation to water. Certainly there are many hundreds of thousands, if not millions worldwide, who will testify to the efficacy of such treatment. Like other complementary therapies, side-effects are hardly, if ever, a cause for concern. How

many deaths have you heard of in relation to complementary therapies as against the numbers of deaths attributable to 'conventional' medicine?

Some therapies have been introduced to the NHS, such as acupuncture and chiropractic, and there have been homoeopathic hospitals funded by the NHS since its inception. However, there are attempts now to limit such funding, part of general cutbacks but perhaps also because of external pressure. When you can make large profits from 'synthetic' why would you want 'natural' to be promoted?!!

A recent news item spoke about a 'break-through' based on mud and the possibilities this may lead to. Of course, rather than using the natural form, these 'possibilities' will be based on synthetic forms, developed to make profit. Yet nature holds the key to so many beneficial treatments that can be accessed simply by all of us. If, to produce a medicine, just one element is extracted from a leaf, flower, root or bark, that element may produce effects that need to be counteracted by synthetic elements. By ingesting parts of plants you can get a naturally balanced treatment.

Many lupus patients, in my experience, have found complementary therapies and natural remedies useful and some extremely useful. My wife and I take colloidal silver – easily obtainable to purchase and in fact cheap and easy to make at home. What did I read recently in the press – a possible 'breakthrough' using a 'silver bullet' to deal with severe and complex health issues. You wouldn't be allowed to make that at home – no profit to the huge multi-nationals! Mayne and I also take MSM, a sulphur-containing product. Add in vitamins, minerals and other supplements aimed at prevention and you have a new game in town – self-managing individuals who are far less likely to need expensive and intensive treatments.

There is an old saying 'we are what we eat.' What we put into our bodies is obviously immensely important. My wife now eats almost entirely organic (even the chocolate is organic so you can tell she is serious!) This has made a great deal of difference. Organic food tends to be more expensive but my wife finds that she needs less quantity, having better quality, the food



being more nutritious and more filling. Because of her links with Sweden she looks at lots of Swedish sites on line and a little while ago she became aware of a doctor in Sweden who treats many diabetic patients. This doctor has found that a 'low carb./high fat' (LCHF) diet has improved their condition to such an extent that many no longer need insulin or use considerably reduced amounts. My wife looked in depth at what was involved, reading and researching tests carried out extensively by open-minded researchers and scientists. She has moved to use this diet as the basis of her eating and found the results very promising. Using coconut oil for cooking (as well as on the skin, in the hair and more - this is a wonderful oil!) has proved beneficial. There is now considerable evidence that the 'low fat' approach does not stand up, and as for the fuss about cholesterol – we need high levels rather than the low levels advocated in recent years. Talk of 'good' and 'bad' cholesterol' is not helpful. Problems arise from sugar not from fat. Current research now indicates that many ideas propounded over the last five or more decades are based on poor studies, inadequate research and proprietary interests.

I don't expect you to immediately agree with or follow the ideas I am advocating. What I would suggest is that you don't assume that everything you see or hear from 'the establishment' cannot be challenged simply because of its source. There are many avenues one can pursue to find 'the other side of the coin,' many accessible easily via the internet. You can look things up for yourself and become a better-informed patient.

I wouldn't go to a homoeopath or an acupuncturist if I needed my broken leg set but I would use them to improve the rate at which the bones knit. Health problems can, and perhaps should be tackled from more than just one angle. I am not advocating that all lupus patients rush off and take their drugs back to their pharmacist. I am not suggesting that wholesale abandonment of prescription drugs in one fell swoop will necessarily be right for all patients. I am suggesting that many might find it advantageous to find out more about a range of treatments and therapies and see

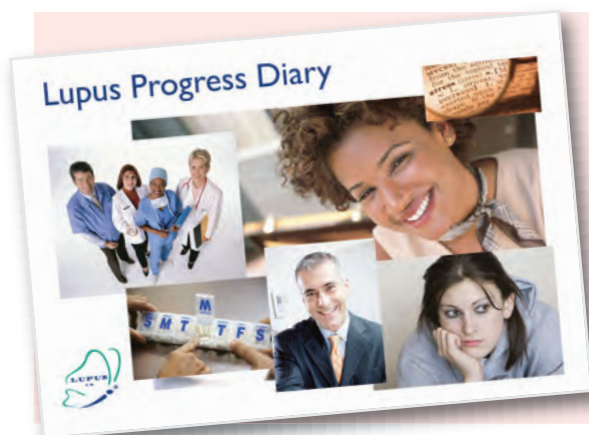
if they appeal, keeping an open mind. Becoming an informed patient can only be beneficial. Taking responsibility for yourself gives you focus and purpose. The expert on you and your lupus is you, not your GP or your consultant, so seek to develop that expertise.

Of course, cost is an important issue. Many of these treatments and therapies

are not available on the NHS; you will have to fund them yourself so that has to be factored into the equation. If you could see a limiting of or improvement in your symptoms would it be worth the cost? That's your decision. My aim is to suggest that you do some checking, personally or through someone close to you. My wife's condition has shown major areas of

improvement over the last three years. If it can happen for her then perhaps it can happen for you. It's worth thinking about.

Always seek the advice of your local family physician or other qualified health professional before starting any new treatment or making any changes to existing treatment.



Lupus Progress Diary - have you got yours?

Now available to members the Lupus Progress Diary, 24 pages to record your appointments, current medications and diary pages.

For your copy please send a minimum of £1 (postage/donation) to LUPUS UK, St James House, Eastern Road, Romford, Essex RM1 3NH together with your name, address and postcode.

TRAVEL INSURANCE

We receive a number of calls at National Office from members who are having difficulty finding holiday insurance. We hope the following will assist:

Freedom Travel*	01223 454290	Go Travel Insurance Services	0870 152 5840	Staysure Travel Insurance	0844 692 8444
Orbis Services	0845 338 1638	Club Direct Travel Insurance	0800 083 2466	World First Travel Insurance	0845 90 80 161
AllClear Insurance Services	0845 250 5250	It's So Easy Travel Insurance	0844 357 1315	The Insurance Surgery*	0800 083 2829
Insurance Choice*	0843 22 78 183	Free Spirit Travel Insurance	0845 230 5000	JustTravelcover*	0800 231 5532
Able2Travel	0845 839 9345	Saga Travel Insurance	0800 015 8055		

Please bear in mind the above companies may not always be able to offer travel insurance. This will depend on the answers given when medical screening is undertaken.

**These companies offer a donation to LUPUS UK when a policy is taken – When enquiring please quote LUPUS UK*

NHS Choices - your Health, your Choice

NHS Choices is a comprehensive information service that helps to put you in control of your healthcare

The service is intended to help you make choices about your health, from lifestyle decisions about things like smoking, drinking and exercise, through to the practical aspects of finding and using NHS services in England when you need them.

It draws together the knowledge and expertise of:

- **NHS Evidence, formerly the National Library for Health**
- **The Health & Social Care Information Centre (HSCIC)**
- **The Care Quality Commission (CQC)**

The NHS Choices service will be at the heart of current

developments to produce a new national digital service covering health, public health and social care. Led by NHS England, the aim is to develop a world-leading, multi-channel service that will create a 'front door' for everyone to engage with the NHS and social care.



Take a look at www.nhs.uk

Information courtesy of NHS Choices

No Pain, All Gain

Words: Sarah Juggins - Illustrations: Zsuzsa Goodyer

We know that staying active is good for you, but how can you exercise when your body hurts? We get some ideas from a physiotherapist who understands the barriers to exercise better than most

When people talk about doing exercise, they usually mean slipping on their trainers and going for a run – or going to the gym to do a workout. However, unless you have experienced the pain of trying to exercise during an arthritis flare-up, you won't appreciate how difficult it can be to undertake even the simplest of movements.

With all the noise about obesity and the perils of leading inactive lives, are there any exercises to maintain a level of mobility, flexibility and fitness that those with arthritis can still do?

Physiotherapist Elizabeth Barker knows all too well just how painful and frustrating it can be to try to exercise when your joints are red and swollen. The 34-year-old has been maintaining her own balancing act – between pain management and keeping fit – for several years.

Here, she outlines six exercises that will help you to stay active, flexible and mobile, without causing undue stress on sore joints. Each exercise comes with an extension exercise if you feel you want to challenge yourself further. Not all exercises are suitable for everyone – consult your GP if you need advice as to which ones are suitable for you.

THE MOVES

1. Sit to stand

Sit in a chair, with your feet flat on the floor and about shoulder distance apart. Without using your arms, move from sitting to standing. Slowly lower yourself back to a seated position. Aim for 10 repetitions, resting as necessary. Try to make the movement as slow and smooth as you can.

- **Extension:** as above, but when you are standing, do three squats, bending your legs slightly at the knees, before sitting down.

2. Leg extensions

Sit in a chair with your back straight and both feet flat on the floor. Moving one leg at a time, straighten your leg by raising your foot



out in front of you. Slowly lower your leg to the floor again. Repeat this 10 times on each leg.

- **Extension:** as above, but when your leg is straight out in front of you, do three small pulsing movements (raising your foot a few centimetres into the air) before lowering.

3. Back mobility

Lie on the floor with your back flat and your knees bent. Your feet should be flat on the floor. Make sure you are



comfortable, so place a rug or an exercise mat underneath your back if necessary. Gently roll your knees from one side to the other. Keep your knees together and roll them as far to the side as is comfortable. Try to engage your core muscles when doing this movement by bracing your stomach muscles and pulling your tummy button towards your spine. Try to keep your shoulders in contact with the ground during the movement. Roll from side to side 10 times.

- **Extension:** try to get your knees as close to the floor as you can when you roll.

4. Bridging

Lie on the floor with your back flat, your knees bent and your feet together, flat on the floor. Squeeze your thighs together and use



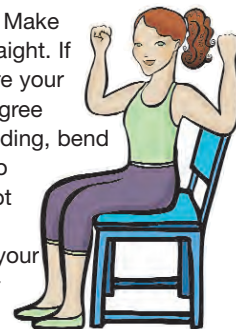
your 'glutes' (bottom muscles) to lift your thighs and bottom off the floor. Hold for a few seconds and then lower your thighs and bottom back to the starting position. Repeat 10 times.

- **Extension:** hold the position for a few seconds longer, or alter the position of your feet to work different areas of muscle. If you place your feet further apart, you will feel the inside of your thighs working harder.

5. Shoulder press

You can do this exercise in a seated

position or standing. Make sure your back is straight. If you are sitting, ensure your knees are at a 90-degree angle; if you are standing, bend your knees slightly so they are 'soft' and not locked. Reach your arms straight out to your sides, level with your shoulders, and bend your forearms upwards to create a right angle. Now push your arms up, so they are extended in a straight line as high as you can reach. Lower back to the starting point and repeat 10 times.



- **Extension:** repeat the movement as above, but hold a light weight – such as a tin of fruit or a book – to give extra resistance.

6. Wall press-up



- Stand up with both feet around 50cms from the wall. Your hands should rest on the wall at about shoulder height, and shoulder distance apart. Keep your body straight and lean it in towards the wall by bending your elbows. Push back to an upright position by straightening your arms at the elbow. Aim for 10 repetitions.

- **Extension:** To give you an increased challenge, move your feet further from the wall. This will mean your arms are working harder with each movement.

These are just some ideas for a simple workout that you can do in the comfort and privacy of your own home. If you have any exercises that you feel people can benefit from, why not write in with your ideas?

FIND OUT MORE

For more info on exercise, download a booklet at www.arthritiscare.org.uk/PublicationsandResources/Selfmanagement/Healthylifestyle

This article by Sarah Juggins was first published in the Winter issue of Inspire (www.inspirearthritiscare.org.uk), the membership magazine of Arthritis Care (www.arthritiscare.org.uk) and is printed with the kind permission of Arthritis Care.



LUPUS UK - Who We Are

David Hopkins, Secretary, LUPUS UK

With the 25th Birthday of LUPUS UK close on the horizon, David Hopkins, Chair, Devon & Cornwall Lupus Group, and recently elected Secretary, LUPUS UK, has taken on the task of compiling the history of our charity.

In November 1990 a group of people who had been involved with lupus and activities aimed at spreading knowledge and information about lupus came together in London. This was the inaugural meeting of the National Committee of LUPUS UK. The meeting was chaired by Dr Graham Hughes, with over thirty others present, from across the UK. On 29th December 1995, LUPUS UK was registered as a charity, holding the first meeting of the Trustees on 20th January 1996, with Ronnie Gourley (Chair), Yvonne Norton (Vice-Chair), Gerald Ansell (Secretary) and Director Brian Hanner in attendance, with apologies from Treasurer Martin Marcus.

That brief historical introduction leads us to LUPUS UK as it is today. The vast majority of the work is done through our paid staff at National Office (NO). We don't own a HQ, renting office space in Romford, Essex. Director Chris Maker joined in 2000 (not originally as Director); many of you have met, heard or heard of Chris. He leads a dedicated and professional Team: Geraldine Leonard started as a volunteer then became a member of staff. She has been with LUPUS UK since 1990 and recently had her job title changed to

Assistant Director, recognising her role in the organisation. In 1994 Janine Hirsch joined, while in 1996 Mary Phillips came on board and in 1997 Christine Watkins was added to the team. Mary and Christine now work part-time. In 2011 Chris gained some male support when a young man called Paul Howard joined the staff. In 2013 Hayley Winter began to work for us.

So you can see that there is a lot of experience in this small Team, with everyone working well and closely with each other. Together they service members and Groups across the UK and lead the work of LUPUS UK.

As a charity, there has to be Trustees, who set the policy, oversee the activities and are legally responsible under the Charities Acts to the Charity Commission. Trustees are elected for three-year terms. Chair of the Trustees is Jane Dunnage from North London. At the end of 2015, Jane will have completed three three-year terms. Vice-Chair is Yvonne Norton, West Midlands. Yvonne has a history of service to LUPUS UK (and before its inauguration to lupus activities) that is without equal. She has been a senior figure in LUPUS UK throughout its existence and has spent

many years involved in European lupus activities. Her contribution cannot be exaggerated.

Looking after the money is Treasurer, Tina Stemp, Hampshire, with David Hopkins, Devon and Cornwall, recently taking on the position of Secretary. The other Trustees are Janet McComiskey, Strathclyde, Karen Newby and Kevin Weston, North Wales and long-serving Trustee, Jan Roberts, North London. Periods of office are staggered to allow for continuity.

You can find out more about the organisation on the LUPUS UK website, which contains all sorts of interesting and useful information. The staff at NO are always very helpful and approachable, so if the need arises please do make contact if local members aren't able to assist. The Trustees are in post as your representatives so don't hesitate to contact any of them.

LUPUS UK belongs to and is for all its members. As the only national charity supporting lupus patients and funding lupus nurses and research throughout the UK, LUPUS UK is unique and special to all of us.

Thanks go to David for writing this article.

A Success Story

Stephen Pendrey's email to Paul Howard

Just thought I would drop you a note to thank you for your guidance with regard to the benefit system; it has made a real difference!! Following the advice you provided, I forwarded this to my daughter trying to get her to take responsibility for her entitlements; this has been no easy feat but slowly she began the claims process.

Over the last three months we have made significant progress and she has been awarded the higher rate of PIP, plus gained her Blue Badge for her car, plus some other 'stuff' that became apparent from all the benefits process and a great bonus was having it all back paid. As a result her confidence has improved so much so that in January this year she started Paediatric Nursing at University.

Once again her confidence was such that she spoke to the University about her limitations due to lupus, this again resulted in her obtaining help at University to attend lectures when she is having a bad day,

taxi to assist with transport and even a lightweight laptop and software!! Great result and again a massive boost for her self-esteem.

We are now in the process of applying for carers benefits as well.

Without your response and guidance this would not have been possible so thank you very much from the whole of our family it has made a real difference and shown my daughter that she does have a voice and does not have to sit in silence. Many thanks for your help.

LUPUS UK has a range of publications produced by an external organisation -

Benefits & Work. The informative guides cover a range of issues relating to disability and benefits. These guides are available free of charge to Members of LUPUS UK upon request. If you are a member and require a guide, please email paul@lupusuk.org.uk requesting the guide(s) you'd like to receive. www.lupusuk.org.uk/living-with-lupus/benefits

Please note, due to the size of the guides unfortunately we are unable to provide physical copies. The cost of printing and postage is too high. You will receive the guides as a digital pdf file.

Let's Dance

Fuelled by popular TV shows such as Strictly Come Dancing and Britain's Got Talent, dance is the UK's fastest growing art form. More than 4.8 million people regularly attend community dance groups each year in England alone.



Whether you like to jump or jive, tap or tango, shake your belly or your booty, dancing is one of the most enjoyable ways to get some exercise. Regular dancing is great for losing weight, maintaining strong bones, improving posture and muscle strength, increasing balance and co-ordination and beating stress. One of the best things about dancing is that while you're having fun moving to music and meeting new people, you're getting all the health benefits of a good workout.

BEFORE YOU START

Most accredited dance schools hold beginners courses and welcome people with disabilities. Schools are friendly and a great way to socialise. If you don't want to go on your own, get a friend to go with you.

Classes can cost as little as £5-10 for a 90-minute session. If the first class you try falls short of your expectations, don't be put off. It's worth trying a few different classes until you find the right one for you.

Wear comfortable clothing that gives you freedom of movement, and shoes appropriate to the dance style. Some classes – such as ballet, tap or jazz – may require specialist footwear, depending on your level. Avoid wearing jewellery – such as earrings, rings and necklaces – which can scratch you or get caught in clothing.

FIND A DANCE CLASS

The easiest way to get into dancing is to contact a dance agency in your region on the Dance UK website

www.danceuk.org/resources/navigating-dance-world/national-and-regional-dance-agencies to find dance classes near you.

Find your nearest school or teacher accredited by the Council for Dance Education and Training (CDET), the national standards body of the professional dance industry. www.cdnet.org.uk

Find a class near you on the **Exercise Movement & Dance Partnership** website <http://emdp.org>. Enter your postcode at the top of the page and get information on times, dates, location and more.

Dance Near You has a database of 1,000-plus dance classes of all levels run by dance teachers, dance schools and studios located across the UK.

www.dancenearyou.co.uk

Search **Youth Dance England's** youth dance directory to find youth dance groups and companies, school teachers and dance events near you.

<http://www.yde.org.uk>

London Dance, set up by the Arts Council England and Sadler's Wells Theatre, has a directory of dance classes offered across London.

<http://londondance.com/directory>

If you can't wait to get your dancing shoes on, visit **Change4Life's** Let's dance section for free online dance routines, games and ideas for all the family.

www.nhs.uk/change4life/Pages/lets-dance-change4life.aspx

To get into wheelchair dancing and find classes near you, contact the Wheelchair Dance Sport Association.

<http://wdsauk.co.uk>

Any form of exercise is helpful for the lupus patient and dance has a wide range of physical and mental benefits. Here three lupus patients speak about the benefits they have gained from taking up dance.

I do Ballroom and Latin. If I didn't dance I would stiffen up. It helps keep me mobile and possibly helps keep my cholesterol levels down. I think if I had not been a dancer and



have a good fitness level I would not have survived multiple pulmonary embolisms which was caused by antiphospholipid syndrome. I had to build up my fitness again after this and it took me two years with light exercise in a gym before I could dance again.

I can do ballroom for an hour but the more strenuous Latin I can only manage for half an hour. This is on a weekly basis. Walking must be a different type of strain on the body because I find walking more of an effort and more painful on areas of the body than dancing. I can get breathless walking up inclines for example or if I walk quickly. This does not happen with dancing unless I push myself too far. I know my limitations and I am tired for the rest of the day but my dancing exercises my brain as

well as my body and I think the feelings of well-being helps to keep my lupus in check. It is an important complimentary therapy to my Hydroxychloroquine and the other medications that help me cope and survive my lupus.

Joan Jackson

I have sle and have tap danced for 15 years and have felt it has got me through so much. Socially, mentally and physically it has given me more than I could have asked for. It can be difficult sometimes but my teachers (I go to two different classes) are aware of the illness and know my limits. I have been in lots of productions and have done many charity events through it.



I would recommend it as it isn't all about lupus that is only one part of me.

Angela Woodhouse

I have been diagnosed with lupus since the beginning of time it feels and have been through its ups and downs. After my last major flare including trial drugs and severe weight gain, I knew I had to do something to help myself.

The gym is boring and isolating as it is a 'on your own' activity. Not for me having been isolated and alone for a long time with a disease that people just didn't seem to understand.

Group exercise takes courage to walk into the right class ... and I mustered up all my courage and fearfully went to one..... exhausted, hurting but with a sense of something I hadn't felt in a long time (endorphin release) - it was Zumba®. The music is uplifting!! So I went again and again.

I am now a licensed Zumba® Instructor teaching seven classes per week in three different programmes (Fitness, Toning and Gold).

Depression and isolation are some of the many symptoms of lupus. Exercise gets the endorphins going and the contagious energy in a group class puts a smile on your face. You meet people, make friends, learn new skills (dance steps), get confident, take control of your body again.

Can't be bad. The support of a group class can be the motivation anyone needs. So, yes! I would encourage anyone to find something they like. Dance based fitness is a good place to start and continue! Tell the instructor of any restrictions you may



have and they will give you modifications. Don't be shy or ashamed, a licensed and qualified instructor is a professional.

Kim Spooner

Please check with your doctor before taking up any form of exercise.

LUPUS UK Centres of Excellence - What? Why? How?

Yvonne Norton - National Vice-Chair & Trustee

The award of LUPUS UK Centre of Excellence is an accolade which is not given lightly. When I devised the concept and set out the criteria, I was determined that not just any hospital with lupus patients should have the title, it has to have a patient-centred Lupus Unit, one where the patient is put first and the medics see a person with lupus, not just lupus.

The clinic and ward facilities need to be top-class. The staff, from consultant down to junior nurse, from therapist through to lab technician, with secretarial support and hospital volunteers, all need to be a Team, working together to provide the best possible treatment and care for all lupus patients coming through the Unit.

The lead consultant needs to apply to LUPUS UK for this recommendation. In this instance, LUPUS UK is re-active not pro-active. When it is considered that all the criteria are fulfilled, on paper, and this includes active research, working with other hospitals, both in the UK and overseas, continual on-the-job training for all Unit members, contact with GPs – it's a long list – an assessment visit is made, usually by three people from Chair/Vice-Chair/Trustee/ Regional Group Chair/LUPUS UK Member.

In addition to the items you would expect to be assessed, there are lots of others that are checked out. From the seating in the waiting area, to the colour of the walls, right down to coat hooks in the toilets, as well as the bathroom facilities on the ward – another long list. If there is something that doesn't get full marks, the award is held back until the item is corrected. Even when all the boxes are ticked and the title is conferred, it doesn't stop there. There is

an annual inspection and all the criteria continue to need to be in place otherwise the Centre will have its Excellence removed. If LUPUS UK gives its name to a Unit it needs to know that its standards are being upheld. If patients attend a Centre of Excellence, they need to know that they will be receiving excellent care in excellent surroundings with no lowering of standards whether in actual treatment or doctor/patient relationships.

There are currently five LUPUS UK Centres of Excellence, four adult centres and one caring for Children and Young People:

City Hospital/Queen Elizabeth Hospital/Birmingham University
Applicant - Prof Caroline Gordon
Official opening - October 2005

Kellgren Centre, Manchester Royal Infirmary
Applicant - Prof Ian Bruce
Official opening - October 2007

Alder Hey Children's Hospital, Liverpool
Applicant - Prof Michael Beresford
Official opening - October 2010

University College Hospital, London
Applicant - Prof David Isenberg
Official opening - July 2012

Louise Coote Lupus Unit, Guys & St Thomas', London

Applicant - Prof David D'Cruz
Official opening - September 2014

An Application has recently been put forward on behalf of the Royal National Hospital for Rheumatic Diseases, Bath. Plans are being made for an assessment visit to take place late Spring.

The establishment of LUPUS UK Centres of Excellence:

- Gives LUPUS UK added kudos in the medical/charity world
- Encourages the medical profession to attain and maintain high standards of patient care
- Gives members confidence that LUPUS UK strives to ensure the highest level of patient care
- Underlines the LUPUS UK motto "Caring for people with Lupus"

If you consider the Lupus Clinic at your hospital to be worthy of being given the accolade of LUPUS UK Centre of Excellence, speak to your consultant and suggest that he/she contacts National Office and requests information on the criteria and application process. If all the criteria can be met, I look forward to visiting your hospital soon.



City Hospital, B'ham: Back: Rebecca Gilman, Jenny Mynett, Front: Biruk Asfaw, Prof Caroline Gordon, Peter Norton, Yvonne Norton



University College Hospital, London: Prof David Isenberg with Jan Roberts, Yvonne Norton & Team Members



Centre of Excellence celebration at Alder Hey



EULAR 2014 - another Conference from a Wheelchair!

Whenever Peter (husband) and I travel to a Lupus Conference there is always a story set around my 'wheels' – Paris, for EULAR, was no exception.

We had decided to travel by Eurostar and had a good journey, arriving at Gare de Nord to be met by a young man from the Assistance Team and a torrential rain storm. The young man told us there would be no problems, he would take us to the front of the taxi queue and we would soon reach our hotel. He took charge of our suitcases, led us to the front of the queue and called up a taxi. The car boot was opened, suitcases loaded, my cushions put inside the car and, as Peter was putting my folded wheelchair in the boot, the driver shouted "No wheelchair, no ride." The suitcases were practically thrown out of the cab and there we were, me on crutches, gradually sinking lower and lower, wheelchair and cushions soaking wet and the young man trying to keep me dry with his umbrella while calling another taxi. In fact, he called four more taxis, each refusing to take my wheelchair. I don't know whether I was more shocked or disgusted that five different cabbies should refuse to carry a wheelchair. Can you imagine that happening in the UK? Eventually, a driver came to us and said his shift had ended but he was sorry for us and would take us to our hotel. Bless him, he probably charged more than the going rate but he did get us to our destination and he did talk to us along the way. The hotel room was very small and very hot but it served its purpose as we would be out each day. The people on reception were helpful, telling us a bus left from a few yards along the road and would get us into Paris in around 10 minutes, the return stop being almost directly opposite. They even invited us to a World Cup Party! Next morning we boarded the bus with ease and discovered that we didn't have to pay – whether this applies to all disabled people or just those using wheelchairs, I don't know. We reached the stop opposite the Conference venue in around 10 minutes but it took 15 minutes to cross the 5 roads (almost in a circle) to actually reach the building. Once inside we were able to register and collect our conference bags and travel passes for the duration of the congress, of course, we didn't have to use these for the bus.

From registration we went to the EULAR Village where the charity/organisation stands are set up to find the LUPUS EUROPE/Lupus France stand was bare –

no leaflets, no posters, no volunteers. I 'just happened' to have a bundle of LUPUS UK bookmarks in my bag so, at least, there would be some lupus information when visitors stopped by and Peter erected the LUPUS EUROPE banner which he found at the rear of the stand. During the 1½ hours we were there, several doctors whom we know came to chat and we were visited by Dr Donald Thomas, author of 'The Lupus Encyclopedia', which he was promoting. I thought that offering a copy of 'Lupus – Diagnosis & Treatment' in exchange for this tome was a good move – it worked! Peter and I had an appointment with reps from a pharmaceutical company so left a note for whoever was due to man the stand. Next day we discovered no-one from Lupus France had been available the first day, however, two of their ladies did cover the remaining 2½ days with delegates from member countries of LUPUS EUROPE calling by in-between lectures.

Following our Meeting, Peter and I went to a PARE session on Political Campaigning during which Neil Betteridge (UK EULAR) spoke about the new EULAR EU affairs strategy, an important topic for European charities.

Next on our Agenda was the opening ceremony which, as ever, began with an introduction to the current EULAR President and presentation of awards to various medics. Suddenly, there was music and bright lights introducing a show featuring acts from The Moulin Rouge. The can-can dancers went down very well with the male delegates while the ladies quite enjoyed the gyrations of the male dancers! This was certainly the best conference-opening that Peter and I have attended over the years! The next day, being the first full day of conference, was very busy with so many scientific, health professional, plenary, PARE and satellite symposia taking place that the programme had to be picked over very carefully to plan the sessions that were of most importance/interest to us

Peter and I had a meeting planned with another pharma company. Following this we went to a PARE session during which Ailsa Bosworth (NRAS) spoke on the importance of transparency when working with the pharma industry and John Church (Arthritis Ireland) spoke about building



successful alliances with other stake holders in the field of chronic diseases. Two important topics for a charity such as LUPUS UK.

Friday was a day with a difference when we went to a nearby hotel where I was interviewed and filmed for a pharma internal training video. Then it was back to the conference hall where Sarah Hewlett, Professor of Rheumatology Nursing, was speaking. Although the session was looking at flares in RA, we felt we should give Sarah our support. For Peter and me our 'main event' was the final session on Friday – Scrutinising the heterogeneity of SLE to optimise patient management – with a 'cast list' of Dr Michelle Petri (USA) speaking of the complex SLE patient, Prof Liz Lightstone (Hammersmith) putting lupus nephritis in focus, Prof Ian Bruce (Manchester) looking at metabolic syndrome & cardiovascular disease and Dr Ronald van Vollenhoven (Sweden) covering the impact of emerging biologics on managing SLE disease subtypes and comorbidities. A very interesting and, to be expected from these excellent medics, informative set of presentations.

In-between attending sessions in addition to those mentioned and popping back several times to the LUPUS EUROPE booth, Peter and I visited other organisations and toured the industry stands to introduce LUPUS UK and find out what, if any, work they are undertaking in the development of lupus-specific drugs.

Saturday morning at EULAR is a 'tidying-up time'. With a lot of delegates having already left and the charity/organisation booths being closed down, this is an ideal time to speak with pharma and industry representatives as they are not allowed to break down their stands until the afternoon. Peter and I had a really nice

couple of hours, being plied with hot chocolate and ice creams by companies who had provided refreshments on their stands and now wanted to clear their 'stock'. A marketing production company had been advertising their services by taking photos of folk e.g. standing with their arms in the air in front of a green background. When the digital photos were printed the people appeared to be swinging on a trapeze, a very clever process. The photographer offered to take a photo of Peter and me but, for obvious reasons, the trapeze shot wouldn't be suitable. I mentioned this would be added to our experience of scaling a cliff in a cage (Summer 2014 News & Views) and the photographer said he had an idea, we were to pose as if Peter was pushing my wheelchair while looking at the camera. The result was three photos, the one I like best being the pair of us 'climbing' a human pyramid.

EULAR being virtually finished, we decided to spend the rest of the day sightseeing. We had been to Paris several times and although climbing the Eiffel Tower was on my 'bucket list' I had been too scared to go into the lift. Now was the time to do it

and we went up to the second level, the highest wheelchairs are able to go. The view was amazing and I had another tick on my list! A cruise along the Seine completed our time in Paris and ended the Conference nicely. Back at the hotel, we packed our suitcases and hoped we would leave Paris in a better way than we arrived. Indeed, we did. The hotel had booked a private taxi service to take us back to Gare de Nord. A mini bus arrived on time, the suited driver shaking hands as he introduced himself. He loaded the luggage then produced a footstool which he insisted on me using to get into the vehicle saying that his Mother-in-Law is disabled and she uses the stool when he takes her out. Once in the taxi, he produced



Level Two, Eiffel Tower

chocolates from the glove box then said, as we had plenty of time and Paris was unusually quiet for a Sunday afternoon, he would show us some of the

sights. The guided tour that followed was a nice ending to the trip as a whole. I did wonder, though, how much extra he would charge on top of the pre-agreed price. We reached the station and I asked "How much?" His response was the agreed fee, 12 Euros less than the inward journey!

EULAR 2014 was an informative and enjoyable conference which ended on a high note, however, thanks to five taxi drivers at the beginning, it could have turned out a whole lot differently. Now, me, Peter and my wheelchair look forward to EULAR 2015, Rome.

Yvonne Norton
UK representative



Climbing the human pyramid

EULAR - European League Against Rheumatism

PARE - People with Arthritis/Rheumatism in Europe

NRAS - National Rheumatoid Arthritis Society Encyclopedia* - USA spelling



HealthUnlocked Forum

The forum has over **6,900** members and is a wonderful supportive environment. If you don't often speak to other people with lupus then this is a chance for you. The website is easy and free to use.

You can join now at www.healthunlocked.com/lupusuk

• TOPICS

This feature helps make it easier to find posts that you're interested in. The topics include; Diet & Lifestyle, Doctor's Appointments, Getting a Diagnosis, Medications, Newly Diagnosed, Symptoms and Work & Benefits.

• AUTO-TAGGING

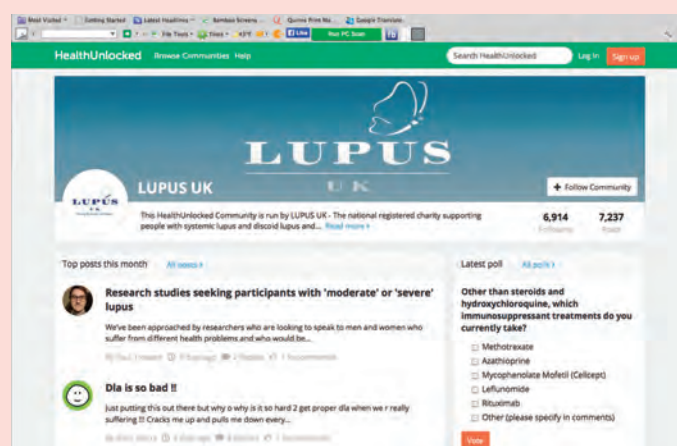
When you write a post or a question, **HealthUnlocked** will automatically suggest words or phrases as key words. This makes it easier to find other posts and questions on the same topics.

• PINNED-POSTS

LUPUS UK can pin posts, so they can be easily found when logging in. This will be used for the most recent LUPUS UK blog post, but can also be used for seasonal information such as information on flu jabs, or for popular questions with good answers.

• RECOMMEND BUTTON

If you think somebody has written a very good post or provided a good comment, you can show your approval by clicking 'recommend' on it.



Lupus Awareness Month Events



South and East Scotland Awareness Event

Panna, Sarah and Lynne from the South and East Scotland Lupus Group held an awareness stand at the Western General Hospital in Edinburgh in October.

It was timed to coincide with Dr Amft's vasculitis clinic and Lupus Awareness Month. Dr Amft sported a LUPUS UK t-shirt for her clinic and joined us afterwards for a photoshoot!

The morning proved very successful. We were able to chat to lots of patients, who either had lupus or had friends or family with lupus. We had a plentiful supply of information leaflets available for people to take home.

Lots of clinicians also came to talk with us and ask us questions, which we were delighted about. Some were keen to learn more as part of their Continuous Professional Development.

Susan Thomson, the newly appointed Lupus Nurse was in the department too. It was her first day in post in Lothian and it was great to meet her. She is looking forward to meeting all the lupus patients who attend the hospital over the coming months.

We were also joined by Stewart, the radiographer from the Brain Research Imaging Centre at Edinburgh University. The University is currently funded by LUPUS UK to study how lupus may affect the brain, and Stewart looked after some of us as participants in the study whilst we had MRI scans.

We look forward to the results once the study is complete. It's raising awareness of what LUPUS UK does, from supporting patients through diagnosis and living with lupus, to supporting research such as the study that is currently underway in Edinburgh, that we were only too happy to enthuse about.

On a final note, for those who we weren't able to meet on the day, there is a regular 'Coffee and Chat' meet on the first Saturday of every month (except January) at 10.30 am. We meet in the Brunton Theatre Cafe in Musselburgh.



Left to right-Lynne Parlett, Sarah Heney, Dr Nicole Amft, Panna Chauhan



Tracy McGuckin, Mari McGregor, Yvonne McGregor, Nicola Smith, Mary Claire Smith and Vicky Hamilton raised £2,500 by taking part in the Great Scottish Run during October

During Lupus Awareness Month Babita Budhathoki, Lupus Society of Nepal, was successful in opening a lupus counselling clinic; a free clinic and volunteer service for people with lupus. LUPUS UK has helped in the past by supplying literature to Babita as she continues to work for those with lupus in Nepal.



Regional Reports



North West

It seems a little late to wish everyone a Happy New Year but the sentiment is the same as it was on 1st January, so Happy New Year!

A couple of quiet months followed an extremely busy LAM here in the North West. We are fortunate with the number of hospitals in the region that support us in our work to raise awareness and therefore invite us with enthusiasm to take our stands and information in for the public and for staff to see what is available for their patients.

It is strange that not being able to finish a hot coffee or a full sandwich is good when you know you have been busy raising awareness in those who don't know about lupus or talking to those who wished they didn't know as they are actually patients themselves. Of course it doesn't end when we pack away as the last thing to do is

make sure there are plenty of bookmarks left in the clinics.

Amidst the hospital visits we held a fund-raising night for the region where a good time was had by all who attended. Those who are 'friends' on facebook enjoyed meeting each other which made the organising of such an event extremely worthwhile. At the end of the evening we released some balloons and wished that the problems of living with lupus could drift away with the same ease. Maybe one day.

The year ended with the Committee enjoying a well earned, relaxing Christmas



meal where we looked back on all we had achieved and what we hoped to achieve in the future.

We are now in the process of organising our AGM and because of the contacts we have made through attending various events we are looking forward to inviting other relevant charities to have a display on the day.

Then it will be onto World Lupus Day in May. No wonder we need diaries!

Of course, we continue to hold our many coffee and chat groups either monthly or bi-monthly. If anyone is visiting the region we hope you know you are more than welcome to join us. We keep them informal but informative.

Hopefully by the time you are reading this any really cold weather will have passed and we will have coped as much as possible. Take care.

Janice McCann



South Wales

Amy Senese took over from Rebecca Griffiths as Chair of the Group on 1st August 2014. A big thank you to Rebecca for all her hard work since she took over from David Clarke.

A Lupus Walk in October at Cosmeston raised over £400! A big thank you to all those who made the effort to take part in the walk, as well as the couple who actually rode all the way from Merthyr Tydfil before completing the four mile walk.

Deborah Redwood-Knight ran in the Cardiff

10K in support of LUPUS UK in September!

Thanks to Diane West for her £100 donation for World Lupus Day! £500 was raised at coffee morning held on 24th June 2014 by Irene Ansell.

A Three Peaks Challenge is currently being arranged so keep an eye out on the South Wales Lupus Group website for more information.

A massive thank you to Rebecca Griffiths for raising over £2,000 after arranging a very

successful fete in Cardiff back in July 2014.

A Butterfly Ball is being held on 17th Oct 2015 at The Parkway Hotel Cwmbran, NP44 3UW for members and non-members. "Get Involved"; come along to support the cause and help raise funds. Tickets are priced at £35.00 per person, please contact Amy Senese on chair@southwaleslupusgroup.co.uk or call 07715 059814 for further information.

Amy Senese

Cambridgeshire

It's rather nice to think that when this report is seen in 'Lupus News & Views' it will be spring as at the moment I'm wrapped up in thermals, watching the snow fall and counting myself rather lucky that I live in a relatively 'low snow' area.

It's been a fairly quiet few months here in Cambridgeshire. One of the disadvantages of having a larger committee is that it's hard to find meeting dates that suit everyone and the colder months bring the usual winter bugs and travel problems. We all keep in touch via phone and email and although our formal committee meetings aren't regular, there are lots of things happening in the background.

Last year we were awarded a grant from the Cambridge University Rag Appeal and have used it to buy a small projector. We have done a few lupus presentations for various clubs and societies recently

and a slide presentation looks much more professional and is easier to understand. Davina (our Vice Chair), who bravely takes on these tasks, says it's much less daunting when the audience's attention is focused on a screen rather than directly at her!

Our regular 'coffee & chat' meetings remain popular and are well attended. I really look forward to these get-togethers and have made some great friends – which certainly helps to lessen the sense of isolation that trying to cope with lupus sometimes brings.

Although we haven't been able to hold many fundraising events, we are extremely fortunate to have the regular support of three businesses that display our collection boxes. The generous donations from The Red Lion at Great Wrating, Elaine's Hair Fashions of Cambridge and Mr & Mrs Upchurch's Farm Shop cover the cost of our

newsletter. We recently had a magnificent donation of over £2000 from two local Masonic Lodges who held a Ladies Night. Lupus is close to the heart of both Masters of the Lodges as one of them has lupus himself and the other has a daughter who has lupus.

We are now beginning to plan our 2015 AGM. As in previous years, we will combine the 'official stuff' with an information afternoon. Judging from attendance figures over the past few years, this format seems to be popular. We have already lined up three great speakers – one of them being a new consultant from Addenbrooke's Hospital.

Finally, a big thank you to everyone who supports our group – our families, friends, members, supporters and the medical teams at Addenbrooke's and Hinchingbrooke hospitals.

Shelagh Cheesman

Strathclyde

On behalf of the Strathclyde Lupus Group committee I'd like to wish everyone a Happy and Healthy 2015. At this time of year the committee start planning for our next AGM and this year it will be held on the 17th April.

Since our last AGM the group has been running without a chair, everyone on the committee has done their bit and ensured

that our group has continued to function well, which has been great, however this is not ideal and I hope this year someone will step forward and take on the role. As well as requiring a Chair, the positions of Vice Chair and Newsletter Editor will also be vacant, so people your help is needed so please give some thought to this. On a cheerier note, our Glasgow and Paisley

meetings remain popular and I hope those of you who do support these continue to do so and perhaps some of you who haven't been before will come along and join us, it's always nice to see a new face, it's also nice to see some "weel kent faces tae", so come along and get to know us.

Karen Allan

Important Dates 2015

TRUSTEE MEETINGS

8 May - The Studio, 7 Cannon Lane, Birmingham B2 5EP

30-31 October - Grange City Hotel, London

NATIONAL COUNCIL

12 September - Grange City Hotel, London

LUPUS UK AGM

9 May - The Studio, Birmingham

LUPUS UK WEST MIDLANDS LUPUS INFORMATION DAY

9 May - The Studio, Birmingham

David Hopkins, Secretary



East Midlands

Hello from the East Midlands. We've had a relatively quiet few months as a couple of committee members are still incapacitated health wise. Never the less we've held a committee meeting and issued our new look newsletter. On that subject, if any members would like to receive a digital copy via email instead of by post to save

costs, please email jilloneill1961@gmail.com.

Fundraising has continued with Brian and Linda Kimberley holding an information stand and sale of knitted goods at their local hospital and as I write I'm surrounded by jars of my homemade marmalade ready to be sold for the cause. Many thanks to Cleon Nelson from Cross Body Leads who, now the total is in, raised £1350 for us at

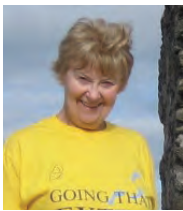
his annual Salsa Night last summer.

Looking ahead we have our Annual General Meeting/ Social on Saturday 11th April 2pm at Kegworth Village Hall and we'd love to see members there.

The group website is now back up and running and can be found at Eastmidlandslupus.org.uk.

Linda Herbert, Treasurer

North Wales



As we get well and truly stuck into 2015, the North Wales Group is busy planning for the year ahead. A date for the diary is Sunday 29 March for the Annual General

Meeting, to commence at 1400 in the Peter Maddison Rheumatology Centre, Llandudno Hospital. We also have a few fundraising events in the planning too. However, as we continue to look forward, I must just reflect a moment on the successes and generosity of a number of our members who have been particularly active throughout 2014.

First of all, Mr and Mrs Fred Weston kindly donated £100, with donations also received from Barbara Hughes and her friend Mrs S Jones. Mr Morgan again, with the kind and enthusiastic support of his friends and customers, donated £110 from the collection box in his shop. Viv and Brian Robinson along with the Weston family ran an information table at Sainsbury's in Rhyl and, as well as passing out a huge amount of information leaflets, raised an amazing £190.40 for the Group.

Sue Conyers has also been busy again, this time running a Christmas raffle and raised a brilliant £250 in the process. Another noteworthy member, Mrs Mary Newby (86), who knits baby and children's knitwear throughout the year for sale at the annual Hospital Table event, helped over two days at the Ysbyty Gwynedd Hospital to raise a staggering £770! My thanks go to each and every one of them for their support, ingenuity and enthusiasm.

On a very sombre note, we unfortunately suffered the loss of Mrs Edith Jones one of our long term members last year. Her husband Mr Raymond Jones kindly donated £350 to the North Wales Group in her memory.

Our Autumn Meeting was held at the Peter Maddison Rheumatology Centre in Llandudno Hospital, on 9 November. This was well attended by our members and again strongly supported by our patron Professor Peter Maddison and Dr Yasmeen Ahmad. As well as the usual business updates from myself as chair and the treasurer, we had short presentations from Rachel Robinson on the importance of Occupational Therapy, the scope and

range of services available and how to get in touch. Eve Newby also gave us a short introduction to magnets for wellness, a potential alternative therapy, (specifically Magnetix products) and explained that they may help members.

The highlight and amazing transformation of the afternoon was during a demonstration by Jean Everden of Changing Faces. Dr Ahmad had found a suitable volunteer with facial discolouration to act as recipient. The transformation was incredible with our guest's discolouration completely camouflaged by very clever blending and application of skin toned makeup. The lady in question was astounded and said she felt very confident and uplifted with the result. All of our members were very impressed with the result and are now aware of this amazing service. Have you seen Changing Faces?

Finally, we await the outcome of the Redrow Homes charity challenge which ran throughout a large part of last year. We are currently developing a range of options that will benefit lupus patients and the newly diagnosed across our region.

Kind Regards, Karen Newby

We invite you to take part in a **WORLD LUPUS DAY** Coffee Morning

Let's try to hold the biggest coffee morning ever for people with lupus!

Join together with other members, family and friends and host a coffee morning on or around World Lupus Day, May 10th.

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.

You can host a coffee morning at home, your local church or community centre, or maybe have a special coffee



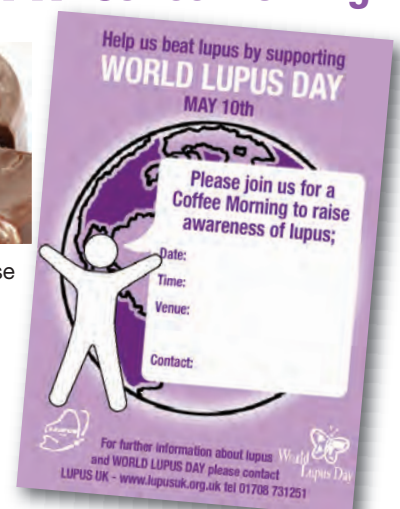
break at work?

You can download a poster to help promote your event from the World Lupus Day section of our website. www.lupusuk.org.uk

For further information or additional help, please email janine@lupusuk.org.uk or phone National Office on **01708 731251**

We can provide;

- Posters/bookmarks
- Collection boxes and balloons
- Tips on hosting a great event





Devon and Cornwall

In my last report I looked ahead to October's LAM activities so will start by mentioning how they

went. Our hospital visits as usual brought us into contact with many members of the public and lots of health professionals. Again this year we handed out to this latter group a notepad and pen, usually with a variation on the theme that 'these pens are preprogrammed and won't work until you have read the leaflets.' This generally brought a smile and a promise to read!

During October I went back to school – several times. It's quite a while since I retired from teaching and spoke at an assembly so looking at a sea of eager faces was exciting. Two videos produced a lot of interest, which I hope will be maintained in positive terms this year. We now have an enthusiastic 'cell' in Newquay, strengthening our Cornish section. At the end of October, Mayne and I joined our friends there for a successful coffee morning at the Headland Hotel – a great venue and very supportive management and staff. We also spoke to students at two medical schools when doing our annual 'presentation' of copies of 'Lupus – Diagnosis and Treatment.' Interestingly, we had several young doctors during our hospital visits say that they had received copies from us in recent years. Another investment in the future.

October gave us the 'highlight' of the Information Day. Media guru Paul joined

Director and Assistant Director Chris and Geraldine, to film the proceedings, now available on the LUPUS UK website. It was a hectic afternoon, with great speakers who gave us lots to think about, lots of camaraderie, a great raffle and a lovely venue. Having our two patrons there was wonderful. MP Alison Seabeck was 'under the weather' but still came and officially opened the event, whilst Christopher Gardner-Thorpe fascinated us with his historical talk.

In November we had our usual round of C&Cs and December brought our last tombola of the year. Then we ended on a 'high' with our Xmas lunch, again at Dartington Hall. Lovely food, lovely company (including a four-month-old, a two-year-old and a five-year old!), musical entertainment and quizzes – a fun afternoon.

We were very fortunate to have a fund-raising '50s fashion show held for us in November in Penzance. Many thanks (again!) to Emma Hill of Pin-Up Boutique and her band of helpers. Thanks too to The Louis Marchesi Masonic Lodge for their donation. Overall, a busy year and a satisfactory one. The list of people to thank is long so we say a general 'thank you' to all who have supported with time, effort and funding.

Our AGM will take place on 18th April and it will soon be spring and summer tombolas and other events to 'get us out there.' George, Diane, Mayne and David will be flying the flag and selling prize-winning tickets, loyally supported by other

members. We have observed at these events and during hospital visits that more and more people have heard of lupus, either just generally or because they know or know of someone with the condition. This suggests two things – first that we in LUPUS UK (many people we speak to are visitors from 'up country') are doing a good job of increasing awareness and second that there are more 'lupies' out there than is sometimes thought.

Following up on the success of last October's Information Day, and to tie-in with LUPUS UK Silver Jubilee celebrations and twenty years of the existence of our own Devon & Cornwall Lupus Group, on 14th November we will be having 'a bit of a do.' Whilst not in The Great Hall at Dartington, we will have a room large enough for 80 to share talks, friendship, lunch and perhaps some surprises. With LUPUS UK Information Days in October and May 2016 being quite a distance from the south-west, we hope folks who joined us (or wanted to be there) from other areas last October will think about coming along. More details in the next N&V or get in touch with me or Secretary Mayne. Those of you who don't get to see our excellent magazine are more than welcome to receive it on-line – just ask.

By the time you read this it will be spring – my favourite time of year! Here's hoping we will all be able to enjoy a great Jubilee Year, celebrating all that has been done and building for an even more successful next twenty-five years!

David Hopkins

LUPUS UK BOOK LIST

Order direct from National Office

Lupus - Your First 100 Questions (Updated edition) (Prof. Graham Hughes)	£2.00	30 pages	Our own Q&A book
Lupus A Guide for Patients (Updated edition) (Prof. Graham Hughes)	£2.00	25 pages	A valuable lupus primer
Hughes Syndrome - A Patient's Guide (Prof. Graham Hughes)	£3.00	63 pages	Comprehensive antiphospholipid
Lupus Diagnosis & Treatment (LUPUS UK)	£5.00	180 pages	An update of The GP Guide to Diagnosis, with expert articles by UK lupus specialists
<i>(Available FREE to Doctors and Health Professionals)</i>			
Talking About Lupus (Triona Holden)	£7.99	220 pages	Patients & Doctors speak
Coping with Lupus (Dr. R Phillips)	£12.50	383 pages	Excellent practical guide
The Lupus Book* (5th Edition) (Dr. Daniel Wallace)	£19.99	294 pages	Big USA seller, now revised
Butterfly and the Wolf (Strathclyde Lupus Group)	£2.00	39 pages	Experiences, Hints and Tips
A Patient's Guide to Lupus (Prof. Graham Hughes)	£5.99	112 pages	Lupus brought right up to date
The Facts - Lupus (2nd Edition) (Prof. David Isenberg & Prof. Susan Manzi)	£9.99	112 pages	In depth look at lupus and its treatments
The Brain and Other Animals (Prof. Graham Hughes)	£5.99	170 pages	Antiphospholipid syndrome case histories

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Up to £5 = £1 Up to £10 = £2.75 Up to £25 = £4.50 Up to £50 = £6.30 Over £50 = £7.50 (UK orders only)

For orders outside the UK please contact National Office for postage costs

* Hardback



Northern Ireland

We send our best wishes for 2015 to all our members and friends of the group.

We are happy to report that 2014 was another positive year for the Northern Ireland Group. The group held two fundraising events in Tesco and Marks and Spencer stores in Co. Antrim and the Committee would like to thank all those who assisted in the fundraising. In



October, the 21 Bridge Club in Newry Co. Down collected £552 for the Northern Ireland Lupus Group which was greatly appreciated. Bronagh Galloghly and Moya Heatley accepted the cheque on behalf of the committee and gave a joint presentation on lupus (pictured left to right, back row Maura Crawford and Dorothy O'Reilly, front row Moya Heatley, Muriel Ferguson and Bronagh Galloghly).

Our AGM in May was enjoyable and informative. Dr. Elisabeth Ball, Consultant Rheumatologist gave a presentation on 'Lupus Joint Disease' followed by a Question and Answer session. The committee changed the date and venue of the 2014 AGM in an attempt to increase attendance and, although the numbers attending did not increase, the feedback was very positive.

On Saturday 17 October 2015, the group is planning to hold an Information Day at the Hilton Hotel, Templepatrick, Co. Antrim and appreciate the advice and support offered

by LUPUS UK and the continued support of our Patron, Dr. Aubrey Bell. Details of the Information Day have yet to be finalised, but the committee hope to secure three medical speakers and one non-medical speaker - we will keep members updated as arrangements are finalised. The committee would be grateful if Northern Ireland Group members would forward their email address to the group's secretary at moyaheatley@gmail.com.

Looking forward, the group continues to lobby for a Specialist Lupus Nurse for Northern Ireland with the help of our Patron Dr. Aubrey Bell, local Consultant Rheumatologists and LUPUS UK.

Finally, the committee was pleased to welcome Bronagh Galloghly and Jennifer Brown as committee members and would like to thank everyone who has helped make 2014 a successful year for the Northern Ireland Lupus Group.

Moya Heatley



South London

Happy New Year everyone. I hope 2015 has started on a pleasant note.

When we discovered a new,

better, warm and comfortable venue in a Cafe called The Coffee Monkey; we resumed Group Support Meetings in October 2014. The Cafe is situated in Central Croydon, opposite the Whitgift Centre and next to the Home Offices but with Croydon being central to the vast Coverage area of the South London Regional Group it makes an ideal starting point/venue. Accessibility is easy by Bus, Tram, British rail, and Street Parking is available. So far this has been well accepted, with one member coming all the way from Birmingham for the December meeting.

On January 10th 2015 we also resumed additional Support Meetings in the Hotung Centre, St. George's Hospital, Blackshaw Road, Tooting, London. This is in conjunction with National Office, and the support and encouragement of Dr. Arvind Kaul, Consultant now in charge of the Rheumatology Department and Lupus Patient Care at St. George's Hospital. The January meeting also went well with Dr Kaul giving a talk on the 'Changes in the NHS as it would affect

Lupus Patients' and 'Coming Changes at St. George's Hospital relating to Lupus/Rheumatology Patients'. Those who came were able to give Dr Kaul some feedback on interested topics they would like to hear.

The Croydon meetings will function as informal drop-in sessions as it a more relaxed venue, and alternate monthly with The Hotung Centre, St. George's meetings which will be more formal with talks to be given. Please look at the LUPUS UK Facebook page for the topics and dates or any date changes.

Also at Dr. Kaul's request the Group have resumed the Support Table for lupus patients on his Tuesday afternoon clinics. It involves one or two volunteers providing literature and or talking/answering questions to encourage and support other patients positively on the clinic. We still need volunteers to help out with this, so please get in touch if you can help out.

The aim is to initially make these Support meetings and unit successful ventures before going on to the next. I just need to keep 'luppy' happy and reasonably well behaved!!!

Adetoun Hughes

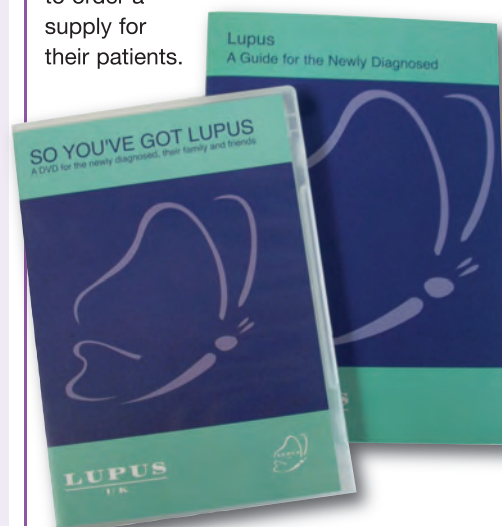
So you've got lupus

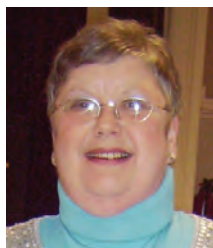
If you have recently been diagnosed with lupus, don't miss our DVD and accompanying booklet for the Newly Diagnosed Patient, their Family and Friends, available from National Office at just £2 to cover postage and packing.

Please send a cheque made payable to LUPUS UK, to National Office together with your name and address and we'll be pleased to send a copy in the post to you. Only one copy per household please.

Alternatively, you can order your copy from our online shop (*still £2 in total to cover postage and packing*).

Medical professionals can call national office on **01708 731251** to order a supply for their patients.





West Midlands

Following the Winter 2014 News & Views, a message was received from a young man offering to help WMLG if

upcoming Meetings/events fit within his university schedule and others have offered assistance, again if events tie in with their commitments. These offers are very pleasing and, hopefully, we will be able to take them up when suitable occasions arise, however, what the Group really needs is a few people to help organise events from the initial stages and see them through, with support, to their conclusion.

At present, there is a Group Committee of four (down from fifteen!) and it has not been possible to organise a Meeting for the past year. It is accepted that, these days, people do not want to be part of a Committee, however, as long as the Group has a Chair and Treasurer, we can keep going if we have people committed to help as Supporters. June and John Oakley are excellent examples of this, John has taken on the role of Membership Secretary and both help with the Lupus Drop-In and are on hand to help with outside Meetings and events by setting out chairs, making coffee, welcoming people and so on. With more help we can climb a few more rungs and put WMLG back to the top of the Regional Support Group ladder.

Thankfully, the WMLG Contact Scheme is picking up again. By the time this magazine goes to press, Angela Edwards, recently appointed Contact, will have had her first Support Meeting in Coventry. Contacts Debbie Atkins (Birmingham) and Angela Williams (Stoke-on-Trent) have been busy taking telephone calls and listening to newly-diagnosed people. Jackie Evans (Herefordshire) is making plans to mark World Lupus Day and Annette Smith (Stratford-on-Avon), Mark Critchley (Tamworth/Male Group) and Helen Eccleshall (Burton-on-Trent/Derbyshire/Young Lupus) are all available to speak with local members. No-one has yet come forward to help with the Shropshire area following the sad loss of long-time Contact, Rose Smallwood. It would be great to have a member attend this year's Contacts Training Course to pick up the reins in Shropshire.

Although the current situation regarding Committee/Meetings is below par (as those who know the history of WMLG will realise), the West Midlands Lupus Group continues to be in the forefront of caring for people with lupus. City Hospital and the Queen Elizabeth Hospital in Birmingham have been home to the first LUPUS UK

Centre of Excellence since October 2005 and continuation of the Award has recently been announced. Rebecca Gilman holds the post of LUPUS UK Research Nurse at City and, the QE, has the services of Sarah Logan, former LUPUS UK Specialist Nurse at Dudley, who organises the Lupus/Renal Clinics. At Russells Hall Hospital, Dudley, Jayne Sullivan is the LUPUS UK Specialist Nurse in the dedicated Lupus Clinic which also has input from Steph Mole, first LUPUS UK Specialist Nurse at Birmingham and, now, Rheumatology Nurse Practitioner at Dudley. The first Lupus Drop-In facility is now in its 12th year at Russells Hall Hospital, having recently moved base to the Clinical Education Centre. There has been a reduction in numbers since the move, however, this may well be due to the cold, wet weather that has, so far, beset 2015. University Hospital, Coventry, also has a dedicated Lupus Clinic with plans for lupus services to be increased. All other major hospitals within the vast area covered by WMLG have a lupus specialist.

Fundraising to continue/extend lupus services within the West Midlands is ongoing with £30,000 being added to LUPUS UK central funding during 2014. So far this year, income has included £300 from Iris Downey's now-famous Table Top Sales, £250 from Oldbury Fundraisers GAYE Scheme, £100 from a Karaoke Evening at the Wagon and Horses pub, Tipton, several smaller donations, including £50 from the Green Token Project at Asda, Coseley, and the most generous member gift of £100. With 12 Golden Bond Runners taking part in the Virgin London Marathon, 26th April, and Oldbury Fundraisers and the Chrystal Golf Club choosing to, again,

support WMLG, the Group may well be on the way to raising a further £30,000 - we hope!

Great news for those who attended the MASTERPLANS Meeting in Birmingham (October 2014) is that on 29th January, the Minister for Life Sciences, George Freeman MP, announced funding of £4.1 million for the MASTERPLANS consortium. Information on MASTERPLANS appears elsewhere in this magazine. If you are within WMLG and would like to be part of this exciting project, please contact Yvonne Norton.

WMLG is hosting the National AGM and Information Day, Saturday, 9th May 2015, at The Studio, Cannon Street, Birmingham. Speakers will include Prof Caroline Gordon and Sarah Logan. Admission is free by ticket from National Office. All will be welcome.

www.westmidlandslupus.co.uk continues to be updated regularly and has a rising number of visitors. The Group Facebook page is used for announcements/information. A recent post announcing the continuation of City Hospital as part of the Birmingham LUPUS UK Centre of Excellence reached almost 4,000 people with 52 likes and 39 shares - fantastic. Thank you to all who help spread the news of activities within the West Midlands. E-mailing the Group newsletter, where possible, is saving time, paper, printing ink, envelopes and postage. Thanks to John Oakley for taking on this task.

Best wishes go to all who support the West Midlands Lupus Group, we wish you good health and happiness throughout 2015.

Yvonne Norton



Sara, Community Life Champion, Asda, Coseley store, presents surprise contribution to Yvonne & Peter Norton from the Green Token Project.



South & East Scotland

Firstly a belated Happy New Year to all of our members.

Our activity for Autumn/Winter 2014 across our region continued but on a much smaller scale. This was partly due to the sudden, unexpected death of my dearly beloved Father and needless to say I had to take a step back. My personal thanks go to all of you for your kind messages, cards, sympathy and support I received during such a difficult time.



As always, thanks to our wonderful fundraisers and supporters.... Firstly, Tina Chapman and her friend organised their joint 50th Birthday Party and decided to raise funds for each of their chosen charities instead of receiving presents. They managed to raise a total of £680 which was split between The Dogs Trust and South & East Scotland Lupus Group. The event took place at Legends venue in Dunfermline Football stadium. Pictured Nicole Chapman, her mum Tina Chapman, friend Cath Herdman and her daughter Kate.

We had dates planned to host Hospital Awareness stands during Lupus Awareness Month at Ninewell's Hospital, Dundee and at Edinburgh. Unfortunately, the three



dates planned for Tayside had to be cancelled due to my family bereavement. I was delighted that Sarah, Lynne and Panna who organise and attend our only regular monthly group meeting in Musselburgh, held a hugely successful awareness day at the Western General Hospital Lupus Clinic

in Edinburgh. Sarah had developed a rash from the fluorescent lights which Dr Amft kindly put her hands over to protect from further damage during the photocall.

Other monies received for the charity included my Father's funeral retiring collection which was split between various named charities of which LUPUS UK received £200.

I also attended a cheque presentation for £250 at Tesco Metro, St Andrews following my successful application to their "Give a helping hand local charity fund" following the recent refurbishment of the store. Ten local charities were chosen and we received good media coverage in the local press. Photo courtesy of Peter Adamson.

Our new Lupus Research Nurse, Susan Thomson continues her induction into her new role at Ninewell's Hospital.

Elaine Stewart, Regional Co-ordinator



Google Searches



Did you know that 'What is lupus?' ranked 7th in the Top 10 'What is....?' category on Google searches during 2014? It's good to know that more and more members of the general public are learning about lupus.

Thanks to Jill and John Moses, Devon & Cornwall Lupus members for pointing this out to us.

Election of Trustees

The maximum number of Trustees allowed in the Constitution of LUPUS UK is eight of whom six are elected from the National Council, being the four officers (Chair, Vice Chair, Treasurer and Secretary) and two Council Trustees. Two Member Trustee positions are nominated through the membership of LUPUS UK.

A rotational system is in place for the election of all the Trustees on three-year terms. A list of the current Trustees may be found on the inside front cover.

The Officer position of Chair and a Member Trustee position become vacant at the year end. Elections for these two

posts, by National Council members, takes place by secret ballot, with the results revealed at the September National Council Meeting in London.

Completed Nomination Forms must be returned to National Office to arrive no later than 1st July.

For Your Information

Helpful Organisations

AntiCoagulation Europe

Tel/Fax: 020 8289 6875
PO Box 405, Bromley, Kent, BR2 9WP
www.anticoagulationeurope.org

Arthritis Research UK

Tel: 0300 790 0400
Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire S41 7TD
Free information and leaflets on most arthritis-linked conditions. Send SAE
www.arthritisresearchuk.org

Arthritis Care

Tel: 020 7380 6500
Floor 4, Linen Court, 10 East Road, London N1 6AD
Aiming to empower people to take control of their arthritis and their lives. Providing clear and accurate information, Helplines etc.
www.arthritiscare.org.uk

Benefits & Work Publishing Ltd

Get the benefits you're entitled to. Plenty of free downloads or subscribe for full use of website.
www.benefitsandwork.co.uk

Benefit Enquiry Line

Tel: 0800 88 22 00
Information on all aspects of the Benefits System
www.gov.uk/benefit-enquiry-line

British Association of Skin Camouflage

Tel: 01254 703107
PO Box 3671, Chester CH1 9QH
Specialist authority on para-medical skin camouflage
www.skin-camouflage.net

British Heart Foundation

Tel: 03003 333311
Greater London House, 180 Hampstead Road London NW1 7AW
Leading UK charity fighting heart and circulatory disease, providing support and information for patients and their families
www.bhf.org.uk

British Lung Foundation

Tel: 03000 030555
Funds research and offers information and support to lung condition sufferers, their families and friends, with more than 120 groups.
www.blf.org.uk

British Red Cross UK Office

Tel: 0844 8711111
Community Services Unit, 44 Moorfield, London EC2Y 9AL
Offering valuable short-term support to vulnerable people in the UK, whether they're recovering from an operation, need a wheelchair or just need help coping around the house.
www.redcross.org.uk

British Sjögrens Syndrome Association (BSSA)

Helpline Tel: 0121 478 1133
Office Tel: 0121 478 0222
PO Box 15040, Birmingham B31 3DP
Self-help organisation for people with SS. A forum to exchange views on how best to cope with living with Sjogren's syndrome.
www.bssa.uk.net

Carers UK

Tel: 0808 808 7777
Provides information and advice on all aspects of caring for both carers and professionals.
www.carersuk.org

Changing Faces

Tel: 0845 4500 275 Fax: 0845 4500 276
The Squire Centre, 33 - 37 University Street, London WC1E 6JN
UK charity that supports and represents people who have disfigurements of the face or body from any cause.
www.changingfaces.org.uk
www.iface.org.uk

Citizens Advice Bureau

Contact your local branch for help and advice

D.I.A.L - Disablement Information Advice Line

Tel: 0800 800 3333
A network of DIAL services providing information and advice for disabled people and others on all aspects of living with a disability.
www.scope.org.uk

Disabled Living Foundation Helpline

Tel: 0300 999 0004
Providing the best possible choice for people who use equipment and adaptations to live a more independent life.
www.dlf.org.uk

Disability Rights UK

Tel: 020 7250 8181
CAN Mezzanine, 49-51 East Rd, London N1 6AH
National organisation of and for disabled people. Campaigning for equal rights for the disabled. Producing a range of publications on disability.
www.disabilityrightsuk.org

Equality and Human Rights Commission

Tel: 0808 8000082
Information and Advice
www.equalityhumanrights.com

Fibromyalgia Association UK

Tel: 0844 887 2444
Everything you need to know about Fibromyalgia, including UK Support groups, pain management, exercise, legal information, research etc
www.fmauk.org

Healthwatch England

Tel: 03000 683 000
Healthwatch England is the independent consumer champion for health and social care in England.
www.healthwatch.co.uk

Hughes Syndrome Foundation

Tel: 020 7188 8217
Conybeare House, Guys' Hospital, London SE1 9RT
Set up to advance public and medical understanding of Hughes Syndrome and to fund further research. Find a specialist in your area
www.hughes-syndrome.org

Irish Lupus Support Group

Tel: +353 (0)1872 4518
Carmichael Centre, North Brunswick Street, Dublin 7
A source of contact, and mutual support to fellow sufferers of lupus in the Republic of Ireland.
www.lupus.ie

London Lupus Centre

Tel: 0207 234 2155
London Bridge Hospital, 27-29 Tooley Street, London SE1 2PR
One of the largest private hospitals in the UK specialising in lupus treatment
www.londonlupuscentre.co.uk

Lupus Canada

www.lupuscanada.org

Lupus Europe

www.lupus-europe.org

Lupus Foundation of America

www.lupus.org

Medic Alert Foundation

Tel: 01908 951045
The registered charity that provides an emergency identification system to protect and save lives.
www.medicalert.org.uk

Miscarriage Association

Tel: 01924 200799
The Miscarriage Association, 17 Wentworth Terrace, Wakefield, West Yorkshire WF1 3QW
Helpline offering information and support following pregnancy loss..
www.miscarriageassociation.org.uk

National Kidney Research UK

Tel: 0845 070 7601
Support through life's ups and downs for kidney patients, their families and carers
www.kidneyresearchuk.org

National Osteoporosis Society

Helpline: 0845 450 0230
National charity dedicated to improving diagnosis, prevention and treatment of this disease.
www.nos.org.uk

NHS 111

Call 24 hours 111 (replacing NHS Direct in England)
The free one-stop number is for patients with urgent, but not life-threatening symptoms.
www.nhs.uk/111

Parliamentary and Health Service Ombudsman

Tel: 0345 015 4033
Free service open to everyone. Set up to investigate complaints that individuals have been treated unfairly or have received poor service from government departments and other public organisations and the NHS in England.
www.ombudsman.org.uk

Patient UK

Internet site providing health information as given by GPs to patients
www.patient.co.uk

PMRGCA UK (Polymyalgia Rheumatica & Giant Cell Arteritis UK)

Tel: 0300 999 5090
Offers support, raises awareness, and encourages research into the two illnesses.
www.pmrcauk.com

Raynauds & Scleroderma Association

Tel: 01270 872776 or 0800 917 2494
112 Crewe Road, Alsager, Cheshire ST7 2JA
Supporting patients and their families, offering support advice and information. Putting patients in touch with each other.
www.raynauds.org.uk

Samaritans

UK: 08457 90 90 90 ROI: 116 123
Samaritans is available to anyone who is in any kind of distress. People of all backgrounds and ages can contact them for emotional support.
www.samaritans.org

Scotland - NHS 24

Call 111 (24 hours)
NHS 24 is a 24 hour telephone health advice and information service for people in Scotland
www.nhs24.com

Scleroderma Society

Tel: 0800 3112756
Bride House, 18-20 Bude Street, London EC4Y 8EE
Support for patients who often feel isolated. Aiming to increase awareness of the disease and to raise money for vital research.
www.sclerodermasociety.co.uk

Stroke Association

Helpline: 0303 3033100
Provides support for people who have had strokes, their families and carers. Campaigning to educate and inform at all levels of society.
www.stroke.org.uk

St. Thomas' Lupus Trust

Tel: 020 7188 7306
Ground Floor, Conybeare House, Great Maze Pond, Guys Hospital, London SE1 9RT
Registered charity supporting lupus research at St. Thomas' Hospital and raising awareness of lupus.
www.lupus.org.uk

Turn2Us

Tel: 0808 802 2000
Charity helping people in financial need access welfare benefits, charitable grants and other financial help.
www.turn2us.org.uk

Wales - NHS Direct Wales

Tel: 0845 4647
NHS Direct Wales (Galw Iechyd Cymru) is the NHS Direct service for people in Wales. It provides information in English and Welsh
www.nhsdirect.wales.nhs.uk/

LUPUS UK Contacts

SCOTLAND

SOUTH AND EAST SCOTLAND	Sheena Edwards	(Borders)	01968 682615
	Miriam Zziwa	(East Lothian)	01316 659786
	Frances Macfarlane	(Edinburgh)	01501 763300
STRATHCLYDE	Elaine Stewart	(St Andrews)	07803 603228
	Karen Allan	(Ayrshire)	01294 604869
	Fiona Cameron	(Renfrewshire)	01505 350516
	Mary Townsley	(Lanarkshire)	01236 731686
GRAMPIAN	Morag Diram	(Argyll)	01838 200392
	*Chris Clarke	(Aberdeen)	07891 620364

NORTHERN IRELAND

CO. ANTRIM	Ruth Hunter	(Newtownabbey)	02890 863432
	Rae Gourley	(Greenisland)	02890 866606
CO. DOWN	Olga Jane Lowe	(Holywood)	02890 427401
CO. LONDONDERRY	*Marshall Lindsay	(Kilrea)	02829 540945

WALES

NORTH WALES	Judith Weston	(Flintshire)	01352 741854
	Lucy Weston	(Flintshire)	01352 741854
	Karen Newby	(Anglesey)	01248 440108
	Ann Williams	(Conwy)	01492 642793
WEST GLAM	Irene Woodhouse	(Swansea)	01792 814233
SOUTH WALES	Maggie Gomez	(Caerphilly)	02920 881551
	*Gordon Davies	(Pontypridd)	01443 404879
MID WALES	Jackie Evans	(Powys)	01497 847257

ENGLAND

CAMBS	Jane Robinson	(Peterborough)	01733 560582
	Davina Frost	(Hardwick)	01954 211679
	Julia Crossley	(Bury St Edmunds)	01638 510885
	Shelagh Cheesman	(Cambridge)	01223 833013
	Shirley Smith	(Swavesey)	01954 230306
DEVON & CORNWALL	Mayne Sundewall-Hopkins	(Torquay)	01803 203318
	Karen Pierce	(Okehampton)	07535 536820
	Olive Robinson	(Torquay)	01803 411691
	Judy Ollis - Carer	(Penzance)	01736 364151
DORSET	Tamsin Campbelton	(Christchurch)	01202 041149
	Jean Durrant	(Okeford Fitzpaine)	01258 860565
	Debbie Steel	(Ferndown)	01202 877390
	Rosemary Smeeton	(Weymouth)	01305 821688
EAST MIDLANDS	Gill Woodford	(Keyworth, Notts)	01159 374168
	Linda Kimberley	(Sutton-in-Ashfield)	01623 552834
	Sylvia Massey	(Loughborough)	01509 266389
ESSEX	Margaret Lawrence	(Melton Mowbray)	01664 668243
	Alison Easley	(Romford)	02085 175688
	*Alan Easley - Carer	(Evenings only)	02085 175688
	Janet Wiseman	(Maldon)	01621 852695
	Jane Barrett	(Epping)	01992 573544
HAMPSHIRE	Heather Smith	(Southampton)	02380 452988
	*Terry Smith - Carer	(Southampton)	02380 452988
	Helen Quick	(Southampton)	02380 320643
	Rose De Carteret	(Guernsey)	01481 721036

HERTS & BEDS	Hazel Wood	(Watford)	01923 801107
	Jane Chaney	(Dunstable)	01525 875326
	Jill Bartlett	(Harpenden)	01582 620139
KENT	Yvette Howell-Williams	(Walderslade)	01634 306266
	Claire Denyer	(Maidstone)	01622 201845
	<i>(Discoid lupus)</i>		
LONDON NTH.	Jan Roberts	(Enfield)	02083 725866
	Edie Duncan	(Edmonton)	02088 071333
	Ola Macauley	(Walthamstow)	02085 588104
LONDON STH	Monique Francois	(Leytonstone)	07940 700704
	Khadi Mansaray	(Thornton Heath)	0203 524 6044
	Adetoun Hughes	(Sanderstead)	02086 578833
NORFOLK	Trevora Monteiro	(Croydon)	01689 331718
	Debbie Grant	(Norwich)	01603 469186
	*Brian Grant - Carer	(Norwich)	01603 469186
NORTHANTS	Carole Chisholm	(Wellingborough)	01933 270109
NORTH EAST	Glenys Ansell	(Middlesbrough)	01642 316096
	Carol Maguire	(Wallsend)	01912 630834
NORTH WEST	Sally Wilcock	(Tyldesley)	01942 892122
	Nasrin Ghayouri	(Bury)	01617 640349
	Caroline Morrison-Pinches	(Blackburn)	01254 691271
	Janice McCann	(Runcorn)	01928 718574
SUFFOLK	Pauline Obi	(Manchester)	0161 279 8616
	Sheila Fincham	(Bury St Edmunds)	01359 251179
SURREY	*Bob Hale	(Framlingham)	01728 724386
	Jill Smith	(Woking)	01932 406049
THAMES VALLEY	Marjorie Nesbitt	(Staines)	01784 460961
	Carol Storrie	(Reading)	01189 670321
WESTERN	Sally Baker	(High Wycombe)	01494 450317
	Jean Castle	(Abingdon)	01865 407838
	Ivy Thomas	(Bath)	01761 412545
	Linda Rumbles	(Yeovil)	01935 840132
WEST MIDLANDS	Sandra Bohin	(South Glos)	01454 883115
	Wendy Cutts	(Taunton)	01460 281398
	Sharon Evans	(Bristol)	01179 401715
	Nyree Kingsbury	(Swindon)	01793 702993
YORKSHIRE	Yvonne Norton	(Coseley)	01902 498236
	Jackie Evans	(Hereford)	01497 847257
	*Mark Critchley	(Tamworth)	01827 331560
	Annette Smith	(Stratford-upon-Avon)	01789 550448
ISLE OF MAN	Debbie Atkins	(Solihull)	0121 242 2571
	Angela Giglia Williams	(Stoke-on-Trent)	01782 305158
	Angela Edwards	(Coventry)	07715 425013
	Janet Green	(Sheffield)	01142 461749
YOUNG CONTACTS	*Hoshiar Singh	(Bradford)	01274 780433
	*Jack and Pat Hirst	(Wakefield)	01924 822740
	Stephanie Smith	(Wakefield)	01262 851703
YOUNG CONTACTS	Terrie Watterson	(Castletown)	01624 825711
	Wendy Gilmour	(Douglas)	01624 623070
	Helen Eccleshall		07912 874587
	Stephanie Matthews		01912 645634
YOUNG CONTACTS	Lucy Weston		01352 741854
	*Chris Clarke		07891 620364

Please note: Volunteer Contacts are available to offer support but as virtually all our Contacts themselves have lupus, it would be valued if callers did not ring after 9pm

(*MALE)

Please Support World Lupus Day 10th May

at 12.30pm e-mail or text the following
message to 10 people you know who do NOT have lupus

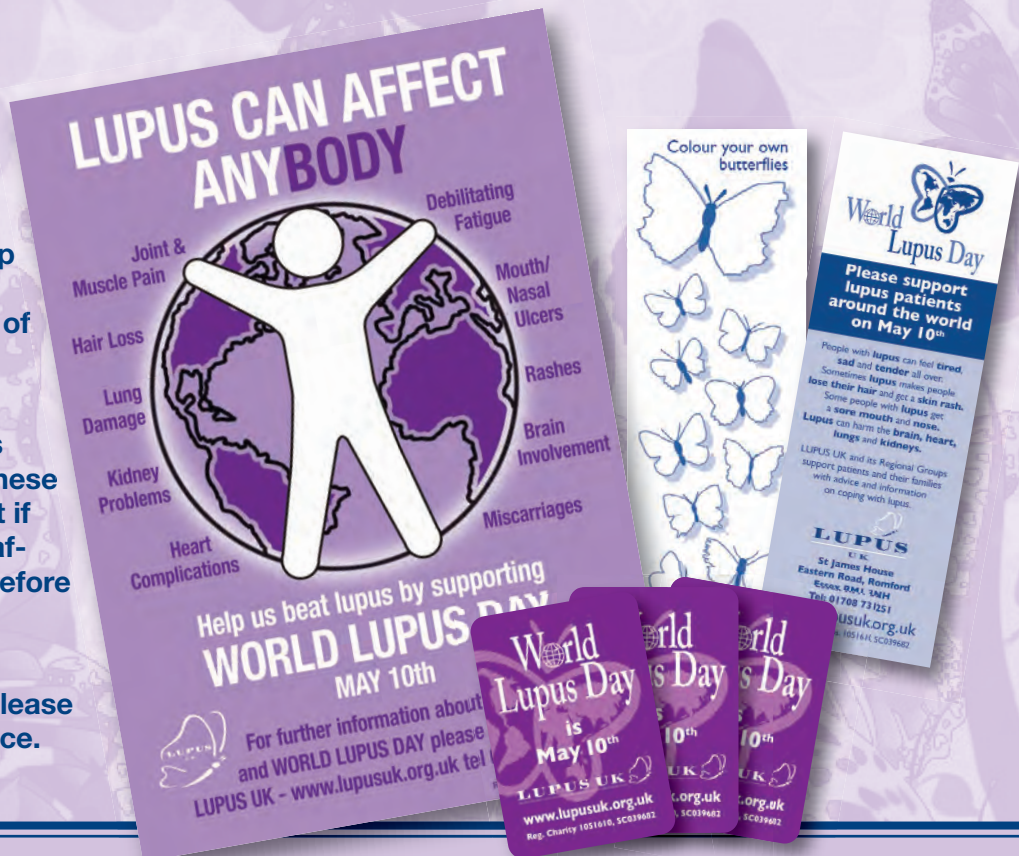
***"Today is World Lupus Day please forward this message to 10 more people
and help spread the message throughout the world Thank You."***

LUPUS UK Reg. Charity Nos. 1051610, SC039682 www.lupusuk.org.uk

Do try to put these up
in a prominent place
during the last week of
April if you possibly
can, thank you.

A sheet of stickers is
also enclosed, and these
will have best impact if
the majority can be af-
fixed on envelopes before
May 10.

If you require further
posters or stickers please
contact National Office.



Do you want to help promote World Lupus Day?

Why not organise an event on the day, no matter how small or large!

Can't make Sunday 10th? Then take a day within the previous or following week.

Take a look at your Fundraising Guide for Fundraising Ideas.

**If just ten more people learn about lupus through you,
we cut into the diminishing number "who haven't heard of lupus".**

Do you have school-age children, grandchildren, nieces or nephews?

If you answer 'yes' to each question, this is what you do:

Make contact with the child's Head Teacher and ask if he/she will display a poster in the school and each child can be given a bookmark prior to 10th May.

If the school will also hold an event, such as a non-uniform day (paying a nominal sum, usually 50p or £1) or a sponsored event (such as walking around the playground a set number of times or collecting litter), that will be wonderful.

The main aim though, is to raise awareness of lupus. Hopefully, the children will read their bookmark then take it home and

show it to their parents - two generations learning about lupus through one action!

When you have the agreement of the Head Teacher, contact National Office with the name of the school and the number of children attending. The bookmarks, which have been produced especially for this project, will be mailed along with a poster either directly to the school or to you, whichever is preferred.

If you can have bookmarks distributed in one school you can go to the top of the class, if you manage more than one school you will be worthy of a gold star!

Further information ring National Office: **01708 731251**