



*Photo: Alan Headland*

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## Welcome

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## A few words from Shelagh

Summer is here and to celebrate we thought we should have a butterfly front cover – many thanks to Alan Headland for allowing us to use one of his beautiful original photographs.

We were pleased to see so many at our AGM in April – it's really heartening and encouraging to see a good turn-out for our events. All our committee members were willing to serve for one more year (mainly due to the large event that we are planning for October – more about that later) and we were also delighted to welcome two new committee members – John Webb and Sharon Elserwy. John will bring a male lupus patient perspective to our committee and he assures me he doesn't mind being the sole male amongst eleven women! Sharon will be our representative for the Peterborough area. We plan to increase our presence around Peterborough, so having another committee member who lives there will help enormously. We are so grateful to John and Sharon for agreeing to join us.

We are now throwing ourselves into the organisation of the East of England Lupus Information Day which will be held in Cambridge on 22nd October. Thanks to the amazing support and enthusiasm we have had from the lupus team at Addenbrooke's hospital, we will be covering a mixed range of lupus related subjects, including managing fatigue, new research and treatments, patient involvement and what patients can do to take control – something for everyone! More details are below.

There is a lot happening in the lupus research world at the moment, including a new treatment that may be trialled at

Addenbrooke's – you can read more about it in Shaista's article on page 11. Clinical trials are so important if we are ever to have a cure for lupus.

Two young lupus patients, Hannah and Caroline, would like to start up a new, very informal group especially for young lupus patients (those in their 20s and 30s). Young lupus patients face many specific challenges such as relationships, careers and plans for a family and we think it's a great idea that they can have the opportunity to get together and support each other. Hannah's contact details are included on page ten.

We are always looking for ideas for the newsletter and a few readers have asked if we can include something about exercising and lupus. We are gathering information and recommendations at the moment and hope to include a detailed article in our autumn edition. In the meantime, if anyone has any further ideas for the newsletter, please do let us know.

Unfortunately Daisy, our regular contributor, isn't too well at the moment, but hopes to be able to resume her 'Young Words' page for the next issue – we all wish Daisy well and hope she feels better soon.

Finally, I hope you all have a lovely summer and I hope to see many of you in October or even sooner at one of our coffee & chat get-togethers.

Don't forget the sun cream!

*Shelagh*



# East Anglia Lupus Information Day

Saturday 22nd October 2016, 1.30pm

The Wellcome Trust Conference Centre  
Hinxton, Cambridge CB10 1RQ

Expert medical speakers from Addenbrooke's Hospital, Cambridge including:

**Dr Frances Hall - Consultant Rheumatologist**

**Dr Thomas Hiemstra - Director, Patient Led Research Hub**

**Dr David Jayne - Head of Vasculitis and SLE Service**

**Dr Natasha Jordan – Consultant Rheumatologist**

Followed by a question and answer session

**This is a ticketed event but tickets are free of charge**



For further details or to book a place email:

[info@lupusuk.org.uk](mailto:info@lupusuk.org.uk)

or telephone Paul Howard on 01708 731251

or Shelagh Cheesman on 01223 833013

Refreshments available. Easy access from the M11. Free parking available.

## Research news

### Belimumab (Benlysta) finally approved for limited use on the NHS

Britain's healthcare cost watchdog has finally approved GlaxoSmithKline's lupus drug Benlysta (belimumab) for limited use, after rejecting it since 2011 on the grounds that it failed to offer good value for money.

The National Institute for Health and Care Excellence (NICE) said on Tuesday that the drug would be made available under a managed access scheme between GSK and the National Health Service (NHS) in England.

This requires the treatment to be reviewed by NICE after three years, during which time further data will be collected on its benefit to patients.

Benlysta, the first new treatment for lupus in a half-century, was approved in Europe five years ago but there has been debate about just how well it helps in treating lupus.

GSK will provide the medicine to the NHS at an undisclosed discount.

**NICE**  
National Institute for  
Health and Care Excellence



### Clinical trial of Lupuzor now enrolling people in Europe and US

Immupharma PLC have announced that Phase 3 clinical studies evaluating the safety and efficacy of Lupuzor — its lead compound to treat lupus — are now getting underway and enrolling patients in Europe and continuing to enrol people in the U.S., where first dosing has already begun.

The pivotal trial, titled *"A 52-Week, Randomized, Double-Blind, Parallel-Group, Placebo-Controlled Study to Evaluate the Efficacy and Safety of a 200-mcg Dose of IPP-201101 Plus Standard of Care in Patients With Systemic Lupus Erythematosus (LUPUZOR)"*, has a total of 45 investigator sites — 10 in the U.S. and 35 in Europe, including Czech Republic, France, Germany, Hungary, Italy, Poland, and the United Kingdom.

"Following the initial US sites being opened and the first Lupus patients having commenced dosing we are delighted that we have hit another key milestone with patient recruitment started in our first European site in France," Tim McCarthy, Immupharma's chairman, said in a press release. "We look forward to providing further positive updates on this Lupuzor Phase III study as it progresses throughout this year and 2017." Lupuzor (rigerimod) is a synthetic peptide that modulates

the immune system of systemic lupus erythematosus patients by modifying the behaviour of some of the key cells involved in the pathogenesis of the disease. Trial participants will be randomly assigned to receive Lupuzor 200 mcg subcutaneously, or placebo, every four weeks for a total of 48 weeks, plus standard care. The trial expects to conclude in December 2017, and to enrol about 200 people.

### Genetic clue to development of mouth ulcers in lupus

The results of a study presented recently at the European League Against Rheumatism Annual Congress (EULAR 2016) showed for the first time an association between a specific genetic pathway and the development of mouth ulcers in patients with lupus. Linking the vascular endothelial growth factor (VEGF) genetic pathway with a specific disease characteristic among SLE patients represents an important step towards unravelling the genetic basis of different SLE clinical presentations.

"Understanding the relationships between specific SLE risk genes and different manifestations of the disease should help elucidate the underlying disease mechanisms and pathways," said Dr Antonio Julià of the Vall d'Hebron Research Institute, Barcelona, Spain. "Understanding more about the genetic pathways which underlie different manifestations of SLE is an important step towards the goal of improving the management of SLE, and ultimately to offer preventative care to individuals at increased risk of SLE," he added.

To identify new genetic variations associated with different SLE phenotypes, a total of 598,258 different regions on the genome (known as single-nucleotide polymorphisms) were genotyped in a population of 482 Caucasian European SLE patients of Spanish origin recruited from the rheumatology departments of 15 Spanish university hospitals belonging to the IMID Consortium (SLE group). A total of 11 clinically relevant SLE phenotypes were tested for association with over 700 reference genetic pathways. In this discovery stage, two genetic pathways were significantly associated with the presence of mouth ulcers and the presence of antinuclear antibodies in SLE.

These two genetic pathways were then tested for validation in a second independent population of 425 SLE patients of the same southern European ancestry recruited from the same Spanish hospitals. In this replication stage, the significant association between mouth ulcers and the VEGF genetic pathway was confirmed.

"Finally, analysing the transcriptional effect of the topical immunotherapies used for the treatment of mouth ulcers in SLE, we found a significant differential expression of VEGF pathway genes," Dr Julià concluded.

## Personal Independence Payment (PIP) applications – patient experiences

Personal Independence Payment (PIP) replaced Disability Living Allowance for people aged 16-64 who have extra care needs or mobility needs (difficulty getting around) as a result of a disability. It is intended to support those in most need to remain independent. PIP is made up of 2 parts, the daily living component and the mobility component. Each component can be paid at one of 2 rates, either the standard rate or the enhanced rate.

If you get either rate of the PIP daily living component, someone who cares for you might qualify for Carer's Allowance. For each component of PIP, you need at least 8 points to get the standard rate or 12 points to get the enhanced rate.

We have heard from several people who have lupus about the difficulties in claiming this benefit and the tremendous anxiety and stress caused by having to go through the very difficult claim process.

Here is Davina's experience:

### **PIP application, the agonising process of getting money to help to live**

*It's hard to know where to start with my story of applying for PIP. I did think about doing so while I still had a job and had had to greatly reduce my working hours in order to 'cope'. Shortly afterwards and I was made redundant anyway despite trying all sorts of ways of working. This was over three years ago now and I wish I had already applied to get PIP before losing my income. At the time it didn't seem right while I was still bringing in a salary, albeit greatly reduced – I felt that the money should be going to those who really needed it. All too soon that became me! Apart from swallowing my pride and admitting that, yes, I was partially disabled by my illness however much I didn't like the label, I needed to stay financially afloat! Should have listened to the friends and colleagues who'd tried to convince me that this was a benefit I was entitled to then! Now it had become a benefit that was indeed meant for people like me. Wasn't it??!*

*It seems the Government has made the process of applying for PIP as difficult as possible for the people who most need it to be made easy. The nearly 40-page claim form arrived from the Department for Work and Pensions (DWP) and almost lost me the will to live! Fortunately for me Cambridgeshire County Council offers a brilliant Welfare Benefits Team (see below for a link). A representative from the team visited me at home (my hero!) and went through all the different benefits I could apply for and then filled out the dreaded forms on my behalf! How brilliant was that??! Not only did he reassure me that I should definitely apply for PIP, he kept plugging away at the process each time we fell at another fence until, finally, over two years later – a medical examination, an appeal and a scary tribunal later he was disappointed that we only achieved the lower rate PIP. I was absolutely delighted with the result! Having read all the horror stories of other applicants being turned down, I'd convinced myself that, despite all his hard work, my adviser would fail to get the PIP for me. I also got a nice big lump sum backdated to my original claim date. The day I went for my tribunal I was feeling so horrible that I didn't stick around to hear the result – I came home to bed instead. My hero adviser stayed to get the verdict and texted me the outcome.*

*Nowadays I hear it's got even more difficult to get the PIP payments we are due. As I understand it you have to be virtually dead... The Government have been caught out by sharp benefits advisers and savvy advice services, serves 'em right for treating us like twits! Kick us while we're down and we'll come back fighting – with quite a lot of help!*

*Thank you Cambridgeshire Benefits Services (one lovely man in particular who might not like his name in lights!), my mum Libby and my best friend Carol who came to the hearing with me and gave supporting evidence. Now I'm going through the whole process all over again – let's see what trip wires the DWP have put in place this time.*

*I'd be happy to talk to anyone who wants more detail of my experiences.*

**Davina xx**

We have also heard from Julie about her experience. Julie was awarded enhanced rate of PIP (she 'scored' 16 points) when she first applied last year. She was awarded this for two years. However, recently she received one of those dreaded brown envelopes calling her in for a reassessment. This time she 'scored' just one point. This meant that her PIP was immediately stopped and she also lost the carer's allowance – a total of £115 per week. Seemingly, according to the assessor, Julie's lupus has miraculously disappeared in just over a year!

Julie immediately asked to see a copy of the assessment and was horrified to read the report. Despite letters of support from doctors and various medical reports, the assessor stated that "there is no diagnosis or specialist input for a cognitive or sensory impairment" – this despite Julie's records stating "daily and chronic fatigue, brain fog, affecting speech". What hope do we all have if an assessor's (who was not a doctor, or even a nurse) opinion is taken over that of a rheumatologist? There were also many other discrepancies in the report. The assessment report also repeated several times that Julie didn't look ill, did not look tired, was cleanly dressed and polite! – maybe if she had been surly and rude she would have scored more points!

Julie's next step, with help and advice from the Citizen's Advice Bureau, was to request a mandatory reconsideration. The CAB was very supportive of her case and told her that she must fight the decision. Pages and pages of supporting documents were sent but the 'reconsideration' was denied. Julie discovered that the reconsideration process included the original assessor submitting a further report – obviously the same as the first one, with no reference made to the additional evidence Julie had supplied.

Julie's next step is an appeal (much the same as Davina's experience), so her distressing and stressful journey continues. Fortunately, she now has the support of her local Councillor and hopefully has made contact with a benefits advisor who will act as her advocate at the appeal hearing.

We want to bring to the attention of all local MP's the nightmare of applying for benefits when suffering from a long term, fluctuating condition like lupus. A recent article in the Cambridge Evening News featured local MP Heidi Allen – she was asking for people to let her know about their experiences of claiming ESA – she said "I would like people to tell me what their experiences are so we can make things better." We did contact Ms Allen to tell her about the reports we had received about the difficulties in claiming PIP, but

## PIP applications – patient experiences...continued

apart from a brief acknowledgment, we haven't heard from her. If you, or someone you know, has gone through the claim process (negative or positive experience), please do get in touch so that we can gather these experiences together and present them to local MPs.

**No personal details (names, locations etc) will be included.**

### IF YOU NEED HELP...

In Cambridgeshire try: [http://www.cambridgeshire.gov.uk/site/custom\\_scripts/fid/fid\\_details.aspx?ID=155618](http://www.cambridgeshire.gov.uk/site/custom_scripts/fid/fid_details.aspx?ID=155618)

Or telephone 01353 612 926

Or contact your local Citizen's Advice Bureau

Or contact LUPUS UK – they have access to guides from 'Benefits and Work' (an invaluable source of information)

## Debbie's skincare tips and advice

My articles are based around all the things I know and love - flowers, beauty and relaxation, simply because I feel they are important. What we surround ourselves with becomes a part of our being, so I'd like to talk about flowers this time.

My favourite thing is shopping for the home. I have become very much a homebody for the most part, not in a boring way but I do love my home and nothing makes me happier than finding a bargain for it. I have pretty much completed the inside of my house and now I am garden planning too.

I liked to call myself a Floral Artist back in the day and being a trained florist as well as a beauty therapist I know what to look for and more importantly what to avoid! If like me you are a fan of flowers (I love roses and tulips) and would like really pretty vases, I found some fabulous ones in *Homebase*, *The Range* and *Dunelm* at very affordable prices. Try to buy a vase that suits the type of flowers you like, not just any old thing! For example - a vase you use for roses wouldn't necessarily be good for tulips: Tulips look better in a more freestyle arrangement, which can be so beautiful, whereas roses need a little more structure - you don't want your roses to flop!

If you are not sure what to do to care for your plants or flowers try and get a good basic book at *The Works* or research online. If living plants and flowers are not your thing



then perhaps take up an artistic hobby (such as card making or collages) your creations can be used to brighten up your home. There are lots of ideas in magazines, or places like *Hobbycraft*.

If things don't come naturally to you then perhaps consider taking a course – look for adult education classes near you. I have taken a few classes and enjoyed them very much. It's great to learn a new skill and to meet lots of different people - it can be great fun.

Indoor herb gardens can be fun – they can be bought in many grocery stores and *Ikea* sell wonderful plant stands and containers. *Ikea* also have some amazing indoor house plants - I have purchased a few and they are still flourishing a year later. For your garden, my suggestion is don't buy randomly – do try to make a plan.

Beautiful things lift the human spirit and plants and flowers can make our homes look alive and fresh – which in turn helps us to relax and enjoy the beauty of nature. Plants and flowers don't last forever of course, but with a little know-how you can learn to get the most from them.

Enjoy this beautiful season and if you are unable to garden treat yourself to some indoor plants, some fresh flowers or even some scented beauty products or candles – surround yourself with beauty x

**Debbie**

### From Debbie's Mailbox....

**Q - I have had most of my foundations and eye shadows for ages. How often should they be replaced? Is it harmful to use eye shadows I have had for years?**

A - Makeup products don't carry a 'best by' date. But they do have built-in expiration dates. Here's a general guide.

When you open a cosmetic for the first time, write the date on the product. It will help you keep track of how long you've had the make up so you'll know when it's time to throw it away.

No matter what products you buy keep them in a safe place out of the sun and keep them clean with lids securely on.

Lip gloss & lipstick are less likely than liquid-based make-up to grow bacteria. It's safe to hold on to lip gloss for at least 6 months and the lipstick for a year. Powders: Unless you notice a funny smell or the colour has turned, you can safely use powder-based products for 18 months to 2 years.

Never ever use mascara or eye shadows past the expiry dates because they do break down and can carry nasty bacteria, the expiry date isn't just so you buy more, it's for your protection. Never risk your eyes remember sight is very precious. I replace my own mascara every 3 months or sooner!

I do not keep loads of cosmetics but when I was training I had a lot and you end up having to get rid of much of it. Hygiene and safe keeping is the key. If you notice a smell, see it separating or have a skin outbreak, then get rid of it. I take great care to clean my lip gloss brush and the top of my foundation bottles. With powder foundations buy a brush - it's much better than a sponge, but either choice you must wash the brush and sponge regularly! If you take great care with your cosmetics you can use them to the expiry date.

Don't keep it forever, buy fresh because all us girls enjoy make-up shopping - right !! Stay Beautiful xx

## Lupus: depression and anxiety

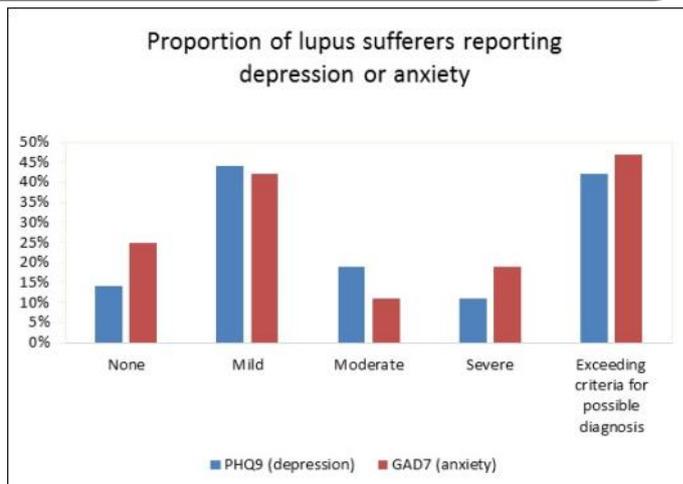
At the meeting of the Cambridgeshire Lupus Group on Saturday 23<sup>rd</sup> April, those attending were asked if they would anonymously complete a couple of questionnaires that are used to monitor for depression and anxiety. The PHQ9 (Public Health Questionnaire No. 9) is recognized as a reliable tool for identifying depression and the GAD7 is an acknowledged screening and severity measure for generalized anxiety.

The questionnaires were returned from thirty-six members who suffer from lupus and from eight carers for someone with lupus. Three other attendees also completed the questionnaire. I wish to thank all who contributed to this brief survey by completing these questionnaires.

The symptoms reported were categorized according to severity (none, mild, moderate, severe) for both depression and anxiety.

### Normal population

Three persons completed the questionnaire who were neither sufferer or carer. Scores for these persons were low and did not indicate depression or anxiety. A 2007 study (1) estimated that at any time about 5% of the general population are experiencing generalized anxiety whilst 2-3% are experiencing depression. Mild depression or anxiety frequently go undiagnosed.



Seventeen (47%) reported symptoms over the threshold score indicative of anxiety. Scores for 11 (31%) of sufferers were consistent with severe or moderately severe anxiety. Nine (25%) reported little or no anxiety whilst a further 15 (42%) reported symptoms of only mild anxiety.

Twelve (36%) of the lupus sufferers reported scores for anxiety and depression that exceeded thresholds for both depression and anxiety.

In this short examination, the proportion of lupus sufferers experiencing symptoms of depression, anxiety or mixed depression and anxiety exceeded that expected for a normal population. Many lupus patients reported no more than low symptoms of either depression or anxiety. A proportion reported symptoms of clinical significance that might merit treatment.

### Discussion

In 2012, The Lupus Foundation of America published an article by Rex Jung concerning lupus and depression (2). Although lupus might contribute neurologically to depression, it is factors shared with other chronic conditions that contributes most to low mood. The UK Government recognises that depression and anxiety may accompany many long-term physical health problems including chronic pain, fibromyalgia, rheumatoid arthritis, diabetes and cardiovascular and pulmonary diseases. Overall, the evidence suggests that at least 30 per cent of all people with a long-term condition also have a mental health problem (3). The survey above suggests that the observed increased depression and anxiety observed in lupus sufferers should be anticipated as for any long-term condition. Depression and anxiety may not be monitored or recognised by GPs, consultants or other health professionals.

Prevention and control of depression and anxiety is associated with increased quality of life. Bel Marra, a US health promotion organization, provides tips for lupus sufferers on reducing depression and anxiety (4) as well as additional tips to help maintain emotional health. This is partly reproduced below.

### Tips to help your emotional health with lupus (from Bel Marra, January 4<sup>th</sup>, 2016)

Below are tips which you can utilize in order to help your emotional health while living with lupus.

- Educate yourself and others about lupus so you can know what to expect and help those around you better understand the disease and how it affects you

Severity	Sufferers		Carers	
	PHQ9 depression	GAD7 anxiety	PHQ9 depression	GAD7 anxiety
None	5	9	2	3
Mild	16	15	5	3
Moderate	7	4		1
Moderately severe	4			
Severe	4	7	1	1
Exceeding criteria for possible diagnosis	15	17	1	2

### Carers

Eight carers completed the questionnaire and scores for six of these carers did not indicate depression or anxiety. One carer exceeded the thresholds for depression and for anxiety: symptoms reported were severe and warranted treatment. One other carer exceeded the threshold for moderate anxiety.

The number of questionnaires from carers is insufficient here to distinguish carers from a normal population or to compare carers with those experiencing lupus.

### Lupus sufferers

Thirty-six who suffer lupus returned the questionnaire.

Fifteen (42%) of these reported over the threshold for moderate depression of which 8 (22%) reported symptoms indicating severe or moderately severe depression. A further 16 (44%) patients reported symptoms consistent with mild depression.

## Lupus: depression and anxiety

- Practice healthy lifestyle habits like exercising, eating healthy, getting rest and avoiding alcohol or tobacco
- Perform activities which you enjoy and that bring you joy and happiness
- Seek support either for lupus or for mood disorders
- Appreciate yourself
- Know your physical limits

With the help of your doctor and your support group you can better help promote mental well-being while living with lupus and reduce your risk of anxiety and depression which does not have to be inevitable.

Long-term carers of people with lupus are often exposed to some of the same challenges as patients; uncertainty; a fluctuating disorder; loss of favourite pastimes; reduced quality of life. It is important for carers to also maintain a good emotional health. Carers should also seek help if they are

experiencing depression or anxiety. It can make a great difference to their quality of life.

### References

1. McManus S, Meltzer H, Brugha T, et al (2007) Adult psychiatric morbidity in England, 2007: results of a household survey. Leeds: The Information Centre for Health and Social Care
2. <http://www.lupus.org/resources/15-questions-depression-and-lupus>
3. Long-term conditions and mental health. The Kings Fund, February 2012
4. <http://www.belmarrahealth.com/lupus-sle-patients-suffer-from-mood-disorders-anxiety-and-depression/>

## 2016 AGM report

The 23rd AGM of the Cambridgeshire Lupus Group opened once again with Shelagh addressing a full house. Our Chair ran through the essential agenda items giving special thanks to everyone who contributed to the continuing success of our group from committee members, which now includes another representative from the Peterborough area and our first male committee member for several years, to fundraisers and participants in events such as this, not forgetting those who wrote fantastic articles for our newsletters. She went on to remind us that we can also access information through Facebook and the national website and our newly launched group website:

[www.cambridgeshirelupus.org.uk](http://www.cambridgeshirelupus.org.uk)

We were reminded of the upcoming information day which will take place on 22nd October at The Wellcome Trust Conference Centre in Hinxton with speakers from the medical profession – further details will follow.

Shelagh was able to announce that permanent NHS funding has been secured for Jane Hollis's post as Specialist Lupus Nurse which is brilliant news especially given the challenges facing the NHS. Jane also works hard to support young patients as well as heading up specialist nurse conferences.

marathon this year to raise funds, some of which goes towards research into targeted drugs for example.

Dr. Natasha Jordan spoke about the relevance and importance of interpreting blood tests in SLE which enable better diagnosis and monitoring of disease activity. She explained that APS has recently been added to the classification list for lupus although not all APS patients also have lupus.

Dr. Jordan told us that there had been tremendous changes at Addenbrooke's in staffing, computing methods and rationalisation of clinics to better oversee all the manifestations of SLE, so now lupus patients generally attend the Monday clinic while nephrology patients are usually seen at Tuesday clinics. She was pleased to be able to tell us that she is supporting a monthly satellite clinic in King's Lynn to include lupus and associated conditions.

Dr Adrian Jackson from the CPFT Psychological Wellbeing Service then spoke about the increase in availability of the service - providing counselling such as Cognitive Behaviour Therapy to those finding it difficult to cope with chronic conditions such as lupus. He said that over 45 therapists had been recruited to offer a self-referral option through the NHS in Cambridgeshire and urged everyone to seek support for stress or depression which can be common amongst lupus sufferers and their carers.

He showed a short self-help film to demonstrate how to try to keep our fears more manageable. You can see it here:

<https://www.youtube.com/watch?v=XiCmniLQGYc>

There followed a useful question and answer sessions which included advice that we will soon be able to access our own blood test results on line.

Thanks go to all who contributed in whatever respect: the crafts stall, tea and cakes, supporting the raffle and making the journey to attend our AGM which ensures the growth and success of our branch and not least to our Chair, Shelagh Cheesman.

**Carol Passell**



'AGM guest speakers (l-r) Chris Maker, Jane Hollis, Dr. Adrian Jackson and Dr. Natasha Jordan

Chris Maker from Lupus UK spoke about the rebranding of the charity after its most successful year yet, both in raising its profile and resulting financial contributions which all go to benefit members - which often include family and friends. Chris told us that 53 people were taking part in the London

## Jacky's Kitchen

Now summer is here and it's a bit warmer, it is lovely to eat outside and have lighter meals like salads and rice dishes. I first tried the courgette cake last year when I had a glut of courgettes in the garden. It really is delicious.

I also love the flavours in this rice dish. It can be served hot or cold and will keep for a couple of days in the fridge. I prefer to remove the Cardamom pods before serving.

All the recipes are free from gluten, dairy, egg, bean, soya and are vegetarian.

### Arabian Pilaff

#### Serves 6

- 1-2 tbs olive oil
- ¼ tsp turmeric
- ¼ tsp ground allspice
- ¼ tsp ground cinnamon
- 1 chopped onion
- 350g brown rice
- 50 g pine nuts
- 25g sultanas
- 6 cardamom pods
- 6 dried apricots (chopped into small pieces)
- 1-1.5L vegetable stock



- Heat oil in large pan and add spices and onion. Fry gently for two minutes.
- Stir in the rice and cook for another two minutes.
- Add sultanas, crushed cardamoms, apricots, and 1L of the stock and bring to boil, stir occasionally.
- (I prefer to lightly break the skin of the cardamom by pressing each one with the back of the spoon until the side is split before adding to release more flavour).
- Cover and simmer until rice is tender and stock absorbed. Depending on the rice this could take between 30-60 mins. You may also need to top up with more stock.
- Finally towards the end of cooking stir in the pine nuts.

### Courgette cake

This is a lovely moist cake and very sweet. To cut down on the sugar you could omit the frosting or just have occasionally as a treat.

- 1 cup brown rice flour
- ½ a heaped cup of quinoa flour
- ¾ coconut palm sugar or brown sugar
- 1 tsp baking powder
- ½ tsp bicarbonate of soda
- ¼ tsp salt
- 1 cup non dairy milk (I use rice milk)
- ¼ tsp apple cider vinegar or white wine vinegar
- ¼ cup olive oil
- 1 tsp vanilla extract
- 1 cup grated courgette

- Pre heat oven to gas mark 6/ 200°C/180 fan and grease a non-stick small loaf pan with coconut oil.
- Mix the vinegar into the milk and leave to stand while you mix the flours, sugar, bicarbonate of soda, baking powder and salt together.
- Add the oil and vanilla to the milk and stir into the dry mixture.
- Stir in the grated courgette. It will be quite a wet mix.
- Pour into pan and cook for 25-30 mins.
- Cool in the loaf pan for about 20 mins before pulling out cake.

#### For the frosting

- ¼ cup coconut oil
- ¼ cup rice milk or another non-dairy milk
- 2 cups icing or caster sugar
- Grated lemon zest and lemon juice to taste

Mix ingredients together to preferred thickness and taste. Ice the top of the cooled cake and sprinkle with grated lemon zest

## Funding secured for Addenbrooke's Lupus nurse



As most of you know, the post of Lupus Nurse Specialist at Addenbrooke's Hospital has been funded by LUPUS UK for five years. This funding has now come to an end.

We are absolutely delighted to share the news that Cambridge University Hospitals NHS Foundation Trust has agreed to take over the funding of the position.

This means that we will continue to have our outstanding Lupus Specialist Nurse, Jane Hollis.

We are sure we are speaking for all lupus patients treated at Addenbrooke's in saying a massive 'Thank You' to the Foundation Trust. We are so lucky to have a specialist nurse at Addenbrooke's and even luckier to have someone like Jane.



## Our grateful thanks to our fabulous fundraisers

We have received some extremely generous donations recently including wonderful sums from **Elaine's Hair Fashions in Cambridge** and the **Lux Solis Masonic Lodge**.

Elaine Williams (**Elaine's Hair Fashions**) organised another sponsored walk and raised an incredible £800 (including a sum sent directly to LUPUS UK through Just Giving).

Elaine and her amazing team of walkers – Chantelle, Mel, Angela, Gaynor, Stewart, Eli, Michelle, Mollie-May, Caitlin and Jacob walked four miles around Waterbeach, stopping for refreshments at The Bridge Hotel, where they were able to hand out leaflets and explain about lupus. The walk then continued to The

Brewery Tap, where Geordie, the landlord, very kindly provided the walkers with much appreciated fish and chips.

"It was great to be able to talk to people about lupus" said Elaine, "and it was a fun way to raise awareness and funds"

Elaine, whose mother has lupus, has supported us for many years and she has agreed that the amount raised will help towards the costs of our information day and also to help fund our newsletter.

We are so very grateful to Elaine, her team of walkers and all the people who sponsored the walk.



'Team Elaine', before...



...and after!

**Lux Solis Lodge No.9781 is a Masonic Lodge** and recently donated £1,000 to LUPUS UK from its charity fund at the behest of its Master Barrie Wilson.



All Masonic lodges collect contributions for charitable purposes. The vast amount of monies are collected at meetings either by alms or raffles or via monthly standing orders. Alms are collected in Gift Aid envelopes which allow Grand Lodge to reclaim tax on all contributions thus swelling the charitable fund pot.

There are charitable festivals organised by all Masonic provinces to which lodge members are asked to contribute. Lux Solis lodge is in the province of Essex. In the province of London the charity in the preceding year was the Air Ambulance Appeal.

In the Lodge of Lux Solis members contribute to these festivals but we also have a tradition of supporting local causes or those which are close to the welfare of our

members and their families. Both the previous Master of Lux Solis Charles Julian and the current master Barrie Wilson are affected by lupus. Charles' daughter is severely debilitated by the disease and Barrie who contracted the disease in 2007 at the age of 60 is now in remission. Both greatly appreciate the excellent help and care received from the Lupus and Vasculitis Clinics in their respective hospitals

The Lupus grant of £1,000 was paid from the Lodge Relief chest which is administered on the Lodge's behalf by Grand Lodge. The year before the Lodges of Lux Solis and its Mother Lodge Stedfast and Unity raised £2,000 for LUPUS UK from a raffle taken at a joint Lodge's Ladies Festival.

**Ed: Barrie has also agreed that this donation can be allocated to our Information Day – an event that really helps and supports lupus patients. We are very proud to have Elaine and the Masonic Lodge as our sponsors.**

**We are so grateful to everybody who raises funds for us. All money raised helps to provide information events, support for young lupus patients and this newsletter. It also helps LUPUS UK fund specialist nurses and research projects. If you have any ideas for future fundraising – car boot sales, coffee mornings, sponsored events, quizzes, concerts, etc, please do let us know. We can help with LUPUS UK merchandise – t shirts (now in an eye-catching purple), balloons and leaflets.**

## Diagnosis criteria for Lupus

At our AGM in April, Dr Jordan showed a slide that showed the current SLICC (Systemic Lupus International Collaborating Clinics) criteria for a diagnosis of lupus. There are now 17 criteria (11 clinical and 6 immunologic). To satisfy, at least 4 criteria should be present with at least one being immunologic criteria. There was great interest in this slide, so for those of you unable to attend our meeting, here is a copy.:

### SLICC<sup>\*</sup> Classification Criteria for Systemic Lupus Erythematosus

rheumTutor.com

Requirements: ≥ 4 criteria (at least 1 clinical and 1 laboratory criteria)  
OR biopsy-proven lupus nephritis with positive ANA or Anti-DNA

#### Clinical Criteria

1. Acute Cutaneous Lupus\*
2. Chronic Cutaneous Lupus\*
3. Oral or nasal ulcers\*
4. Non-scarring alopecia
5. Arthritis\*
6. Serositis\*
7. Renal\*
8. Neurologic\*
9. Hemolytic anemia
10. Leukopenia\*
11. Thrombocytopenia (<100,000/mm<sup>3</sup>)

#### Immunologic Criteria

1. ANA
2. Anti-DNA
3. Anti-Sm
4. Antiphospholipid Ab\*
5. Low complement (C3, C4, CH50)
6. Direct Coombs' test (do not count in the presence of hemolytic anemia)

\*SLICC: Systemic Lupus International Collaborating Clinics

\* See notes for criteria details

## Sun protection tips



It's the time of year again to start thinking about sun protection. Here are some tips:

- The sun is strongest between 11am and 3pm so try to minimise sun exposure at this time. Do outside activities such as gardening or walking your dog in the morning or late afternoon.
- Apply sun cream with a sun protection factor (SPF) of 50, that blocks both UVA and UVB, 15 minutes before going out in the sun. Reapply, as sun cream wears off especially with sweating, swimming, exercise or drying the skin.
- Cover up exposed skin as much as possible by wearing a wide brimmed hat, long sleeves and lightweight scarf to cover the 'V' area of the neck. Sunglasses are also recommended. Thicker weave clothing also helps to block out the rays.

- Find shade as much as possible under trees, canopies or indoors, remember to still use sun cream in the shade as the UV rays can be reflected upwards off other surfaces onto your face.
- Carry a small tube of sun cream with you so you can top-up as required.

The sun's rays can affect your skin even on a typical British day when the weather is overcast, which feels like most of the time at the moment!

Factor 50 sun cream is available on prescription so talk to your GP when you next see him and ask whether he would be willing to add it to your prescription as part of your preventative care.

*(Taken from an article by Jane Hollis first published in our Summer 2012 edition)*

## New group for people in their 20s and 30s with Lupus

Hello!

My name is Hannah, I'm 25 years old coming up to 26. I have had lupus now for nearly 9 years.

I recently went to the information meeting on April 23rd. It was a very interesting afternoon and I made a lovely new friend Caroline, in her early 30s. It made me think about starting up a new group for people more around our age. I did attend the young lupus group run by Jane Hollis which was great and I've heard about coffee mornings but nothing specifically for people around my age. I thought it would help to meet with people to discuss things or just have fun, whether it is in a social place or a room hired out.

I would love to hear from anyone who is interested in getting this going. Please email me if you would like to join in! Any ideas would be gratefully appreciated. My email address is [xhanix\\_no.1@hotmail.com](mailto:xhanix_no.1@hotmail.com).

Look forward to hearing from you! X

Hannah

## We have a brand new website!

We are excited to announce that our new website is now live! As well as having a brand new look, it's a lot easier to navigate and it works as well on mobiles as it does on desktops. Our branding has also had a lick of paint too – the new LUPUS UK purple!

We will continually expand our online content to keep you updated with the latest information and newest projects, so check back often.

We hope you will enjoy our new site. If you have any questions, comments or suggestions we would like to hear them so please send them our way.

[www.cambridgeshirelupus.org.uk](http://www.cambridgeshirelupus.org.uk)

**Ed: A huge thank you to Niall for designing it – and managing it for us until we learn how to use it!!**

LUPUS  
UK

CAMBRIDGESHIRE LUPUS GROUP



## Immunoabsorption: notes on a pilot study

**April 21, 2016**

I could have slept for days this morning but I hoiked myself out of bed and tumbled down the stairs where Shelagh the Wonderful was waiting, with husband Gary parked just outside, ready to whisk us both off to Addenbrooke's for a meeting. I won't mention Gary's shorts here because even thinking about bare legs in the middle of a windy April makes me feel cold.

Before the biscuits arrived, we gathered at the Clinical School: \*we\* constituted five lupus patients, one researcher, Biljana Brezina, one consultant, Dr David Jayne, and one (only one of her kind) Jane Hollis. This was our second rendezvous - discussing communication strategies for a pilot study of a new treatment for lupus.

Let me interrupt myself here. When you hear the words 'new treatment', what do you think? How do the words make you feel?

I don't think there is one among us who doesn't accept that a diagnosis of lupus almost instantly confers Guinea Pig Status upon us. The nature of the disease, rare, misunderstood by medics and non-medics alike, is to fling us into a world of trial (by blood, if not fire). Steroids, which have been employed for decades in the treatment of lupus, are no friend to me. Injected with grams of the stuff during my teenage years, steroids precipitated glaucoma in me. Cue years of eye operations, and cleverly engineered devices in both eyes. Hydroxychloroquine caused hallucinations and precipitated a worse flare. Azathioprine resulted in leukopenia - lowering of white cell count; 'leuko' meaning 'white' and 'penia' meaning 'deficiency'. Tacrolimus caused haemolysis - another term of Greek origin, with 'haem' referring to 'blood' and 'lysis' meaning 'loosing' or 'setting free' - referring to the rupturing of red blood cells (erythrocytes) and the release of their contents (cytoplasm) into the surrounding cellular fluid (blood plasma). I am deliberately mentioning these terms and their meanings because, as lupus patients, we are introduced into the world of Latin and Greek terminology whether we have linguistic inclinations or not.

Back to the new treatment. It is called Immunoabsorption. Our first meeting with Biljana, who is the researcher in charge of conducting this pilot study, was held on the 19th of August, 2015, during which we discussed what Immunoabsorption or IAS involves: it is an intravenous filtering process; a form of plasma exchange, but unlike normal plasma exchange which simultaneously filters out helpful and harmful proteins, IAS removes only the harmful auto-antibodies that cause damage, irritation and inflammation to our muscles, joints, kidneys, skin, eyes, lungs...oh, you know, on and on.

The affliction of lupus is to have an abundance of the wrong sort of antibodies. Antibodies are our main line of defence. To have a line of defence facing inward, instead of outward, means we are being attacked by ourselves. By our cells. By auto-antibodies. So a treatment that proposes to selectively filter out these ill advised auto-antibodies sounds a clever process to me.

During our first meeting, some of the medical explanation and jargon threw up problems for us patients. Terms like 'invasive' and 'washing of the blood', for example, aren't exactly designed to bring comfort! A new treatment invariably brings with it the usual anxieties of a life of unresolved illness laid bare and vulnerable, but the concept of a trial which does not involve violent side-effect inducing drugs is heartening.

According to David Jayne, nephrology consultant at Addenbrooke's, Immunoabsorption has already been used to good effect in kidney transplant cases, and patients with vasculitis, but lupus being as varied and variable as it is, no randomised studies have yet been carried out on lupus patients. The pilot study being proposed by Biljana would be the first of its kind. The most robust, rigorous trials are placebo controlled, double blinded, randomised and involving a large number of participants.

We discover during this, our second meeting, that the project proposal has been submitted for funding. We discuss eligibility criteria (too complex to detail here), the number of intravenous sessions necessary (7 sessions in 14 days – quite intensive but auto-antibodies are tricky little devils, which reassert themselves very quickly) and stumble over the concept of a placebo control – it seems almost cruel to subject 15 of 30 patients to cannulas inserted for no good reason. Well, except that we, at Guinea Pig Central, are used to having all manner of tests, scans, needles, toxic drugs, with often very little progress or positive outcome to show for them. On the other hand, life saving treatments are discovered in just such trials as these.

My life has turned on a dime, as the Americans say. On Rituximab and IVIg (intravenous immunoglobulins) to be specific. Sometimes I have moments of pure bliss. As the moment passes into normalcy, I recognise what lies at the heart of my bliss. I am no longer constrained by daily immuno suppressive drugs which torment me far more than they heal me. Rituximab, given intravenously every few months, releases me from the bondage of Methotrexate and Cyclosporine, Azathioprine and Mycophenolate.

BUT I am perfectly aware that these very drugs are wondrous for other patients. Well, perhaps not wondrous... We aren't discussing sublime flavours of ice cream and cupcake here. Certainly helpful, relieving.

So where do we find ourselves now that the biscuits have been eaten, the proposal thoroughly discussed, and our goodbyes said? I think the crunch may lie in that pesky eligibility criteria I mentioned earlier. Many of us may bravely put forward our naked arms and set aside time and travel in the name of research, but how many of us will fit the required model for IAS to work best? Shall we simply be brave and set forth into the unknown?

**Shaista Tayabali**

[www.lupusinflight.com](http://www.lupusinflight.com)

# Thank You...

## (Fundraising and Donations)

Mrs C Barrere	£40.00
AGM Collection Boxes	£25.15
AGM Crafts & Cakes	£99.55
AGM Raffle	£132.00
Mrs J Ghirardani	£45.00
Red Lion, Great Wratting	£187.35
Elaine's Hair Fashions	£740.22

We are so grateful to all those who fundraise for us – any ideas for future fundraising would be appreciated.

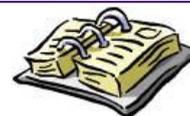


Don't forget that we have a Facebook page where you can find our diary of events, pictures, discussions, handy tips and lots of fun things.

Search for:

**Cambridgeshire Lupus Group**  
on [www.facebook.com](http://www.facebook.com) and join us.

## DIARY DATES



Saturday 2<sup>nd</sup> July 2016 - 11.00am **Cambridge Coffee and Chat**  
Sunflower Restaurant, Scotsdale's Garden Centre, Great Shelford, Cambridge.  
*Contact Shelagh for details*

Saturday 16<sup>th</sup> July - 11.00am - **Peterborough Coffee and Chat**  
The Restaurant, Van Hage Garden Centre, Peterborough Garden Park.  
*Contact Jane or Sharon for details*

Saturday 6<sup>th</sup> August 2016 – 11.00am – **St Ives Coffee & Chat**  
The Dolphin Hotel, London Road, St Ives.  
*Contact Shelagh for details*

Saturday 20<sup>th</sup> August 2016 - 11.00am - **Fenland Coffee and Chat**  
The Cross Keys, Market Street, Chatteris.  
*Contact Shelagh for details*

Saturday 1<sup>st</sup> October 2016 - 11.00am **Cambridge Coffee and Chat**  
Sunflower Restaurant, Scotsdale's Garden Centre, Great Shelford, Cambridge.  
*Contact Shelagh for details*

Saturday 15<sup>th</sup> October 2016 - 11.00am - **Peterborough Coffee and Chat**  
The Restaurant, Van Hage Garden Centre, Peterborough Garden Park.  
*Contact Jane or Sharon for details*

Saturday 22<sup>nd</sup> October 2016 – 1.30pm.

### **East Anglia Lupus Information Afternoon**

The Wellcome Trust Conference Centre, Hinxton, Cambridge CB10 1RQ

*More details inside this issue*

**You don't need to let us know you are coming to any of our coffee and chat meetings – just turn up!!**

## COMMITTEE AND CONTACTS

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Please use our group email address: [mail@cambridgeshirelupus.org.uk](mailto:mail@cambridgeshirelupus.org.uk) to contact any committee member or any of our contacts. Please respect the fact that most of your committee and contacts have lupus too. Calls should be between 9am and 8pm.

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GROUP 

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