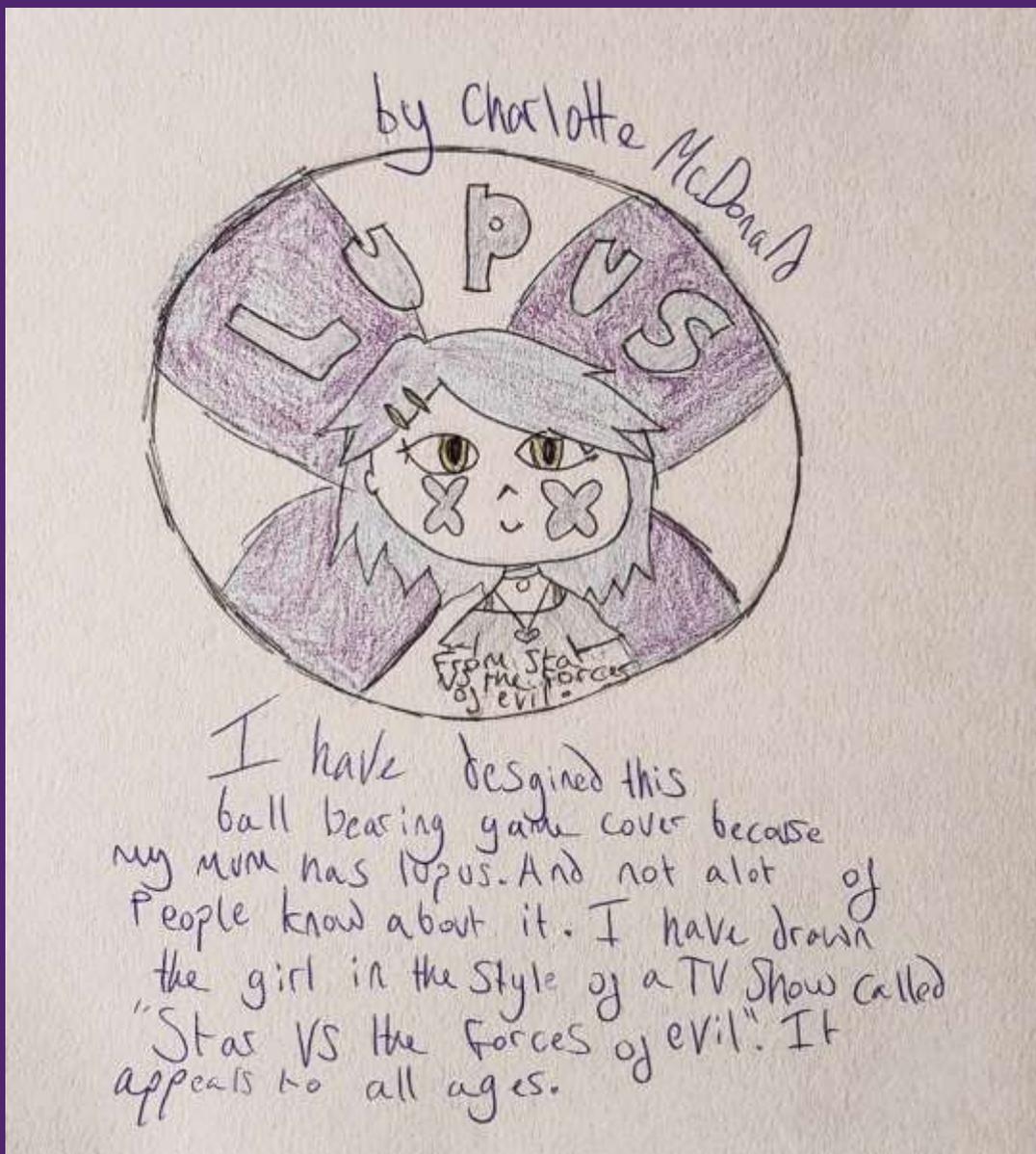




# CAMBRIDGESHIRE LUPUS GROUP

Autumn 2018



## Welcome

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## A few words from Davina

Firstly, some words from the latest recruit to our committee here in Cambridgeshire, Dr Sara Booth, MD FRCP FRCPE, on work she has been doing to elucidate the injustices those with some rare diseases face.

When people with Lupus get together, whether virtually on the web, or at a support group meeting or sitting in out-patients waiting for their appointment, commonly the subject turns to how little their illness is understood or known about. It's not very common so this is not surprising, but there are lots of illnesses which share some characteristics with Lupus – its *invisibility*, the way it *fluctuates* and causes *crushing fatigue* at times. This ignorance is not surprising (though it can be very hurtful) in lay people but it causes major difficulties when those in government and its agencies make law based on hunch, prejudice and the desire to pander to powerful lobbies. We're trying to raise awareness of Lupus and the difficulties it causes, starting in Lupus awareness month. Join in, let's make some changes! See ideas on our Facebook page and website .....Facebook: Cambridgeshire Lupus Group, website [www.cambridgeshirelupus.org.uk](http://www.cambridgeshirelupus.org.uk) Twitter: @lupuslives

Sara Booth

### Fundraising news

The Cambridgeshire group has had quite a busy fundraising summer! Since 'a picture is worth a thousand words' this season we have a few tell-all snaps.

What never ceases to amaze me is how generous the great British public are. Local schemes have been coming up trumps for us this season and I have shown these efforts in our report and this newsletter.

Applying to the Cambridge Building Society for their Cash for the Community resulted in a massive donation of £709. Members of the public collected tokens published in the Cambridge News and on-line; and sent them in for their chosen charity.

And then there was the local Waitrose scheme, collecting green tokens at the checkout and donating them to their preferred charity. That raised an amazing £284 from the public!

Cambridge local independent radio station, Cambridge 105, gave us the opportunity to be interviewed on live radio and talk about Lupus. John and Lara, upcoming media stars, did a brilliant job and were on-air on the new 'Sunday Brunch' slot discussing all things Lupus!

### Anyone for cake?

Lara McDonald, our wonderful Social Secretary has done a particularly sterling job raising funds recently, in addition to entering us into the above schemes. Lara is undoubtedly our 'Star Baker' this season – and she does make exceedingly good cakes too. Thank you Lara!

*"When autumn darkness falls, what we will remember are the small acts of kindness: a cake, a hug, an invitation to talk, and every single rose. These are all expressions of a nation coming together and caring about its people."*  
Jens Stoltenberg

### SAVE THE DATE:

**Cambridgeshire Lupus Group will be holding their next Lupus Information Day on Saturday 20<sup>th</sup> March 2020. We do hope you will save the date and come along. More details will follow next year.**

Happy Autumn all!

Davina x

## Our Front Cover

A great big thank you to Charlotte McDonald, daughter of our Social Secretary Lara, for her design of a ball bearing game cover to raise awareness of Lupus with her fellow pupils.

If you have any photos you would like us to share either for the front cover or within a newsletter, please do email them over to us. It is always lovely to read and see what our members' have been up to; whether it is at work, rest or play!

## Flu Season Advice

Flu season will soon be upon us once again. To answer any questions you may have about the influenza vaccine Sue Brown (formerly lead specialist nurse in Rheumatology at the Royal National Hospital of Rheumatic Diseases in Bath), Jane Hollis (Lupus Nurse Specialist at Addenbrooke's Hospital), Dr David Jayne (Professor of Clinical Autoimmunity at Addenbrooke's Hospital), Dr Kate Armon (Consultant Paediatric Rheumatologist at Addenbrooke's Hospital) and Dr Rona Smith (Clinical Lecturer in Nephrology at Addenbrooke's Hospital) have written the following article for us.

### Why is the flu jab important in lupus?

For most people, flu is not usually serious and recovery is often expected within a week. However, for certain groups of people, especially those with diseases of the immune system such as lupus, symptoms can last longer and there could be an increased risk of developing complications such as bronchitis or pneumonia. The flu vaccine is available free of charge to everyone with lupus in the UK in order to protect you from the flu and any potential complications.

### My partner has lupus. Should I have the flu vaccination as well?

This depends very much on how unwell your partner is with lupus, so it would be sensible to discuss this with your GP. It is possible you may be offered the flu vaccine in order to prevent any risk to your partner.

### Will the flu vaccine cause my lupus to flare?

Sometimes the vaccine may make your symptoms a little worse, but this should settle in a few days. You cannot get flu from the flu vaccine as it does not contain live viruses.

### Am I entitled to a free influenza vaccination because of my lupus diagnosis?

Yes. Patients who have lupus fall into the high risk group. They may be on immunosuppression, on steroids, and lupus disease will classify as being immunocompromised.

<https://www.gov.uk/government/collections/annual-flu-programme>

NHS England has recommended that adults aged 18 to under 65 in clinical at-risk groups are offered the quadrivalent influenza vaccine which protects against four strains of flu. *This reflects current JCVI advice and Green Book guidance that was updated in October 2017 on the basis of cost-effectiveness data produced by Public Health England.*

NHS England has recommended that the adjuvanted trivalent influenza vaccine (FLUAD) be made available to all those aged 65 and over in 2018/19. This is the most effective vaccine currently available for this group. *This reflects current JCVI advice and Green Book guidance published in December 2017 by Public Health England. Note: JCVI considers FLUAD to be more effective and cost-effective than the non-adjuvanted vaccines in the elderly (including quadrivalent vaccine).*

### What do I do if my GP Surgery won't give me a free influenza vaccine?

Discuss with your lupus team at the hospital who could send a copy of Department of Health guidelines to your GP with a letter of recommendation.

### How does the flu jab work?

The flu jab causes your body's immune system to make antibodies to fight the flu virus.

Antibodies are proteins that recognise and fight off germs that have invaded your blood, such as viruses. If you catch the flu virus later on, the immune system will recognise it and immediately produce the antibodies to fight it. It may take 10-14 days for your immune system to respond fully after you have had the flu injection. The antibodies against the flu strains will gradually decrease over time and the flu strains can change from year to year.

### I was immunised last year. Do I need to be immunised again this year?

The flu virus continually changes and different types of flu virus circulate each winter, so it is recommended that you should have the latest strain of flu vaccine by intramuscular injection every year.

The World Health Organisation (WHO) makes an assessment every year of the strains of flu virus that are most likely to be circulating during the following winter. Based on this assessment, WHO recommends which three flu strains the vaccines should contain for the following winter. These flu jabs are used for the countries in the northern hemisphere, not just the UK.

## Flu Season Advice (continued...)

### **I don't normally get the flu so do I really need to be immunised?**

Yes. Everyone can benefit from getting a seasonal flu vaccine every year. This improves your chances of having a flu free season and also avoids transmitting the virus to those at high risk.

### **Is the vaccine safe?**

Yes. In all countries including the UK, all vaccines must go through a rigorous testing process, and meet stringent safety standards, before receiving approval for manufacture. After WHO recommendations are available, production of the vaccine starts in March each year and is usually available from your GP.

### **Who should NOT have the flu jab?**

You should NOT have the flu jab in any of the following situations:

- If you have ever had an allergic reaction to a flu vaccine or one of its ingredients. This happens very rarely.
- If you have had a confirmed very serious (anaphylactic) reaction to egg, have an egg allergy with uncontrolled asthma or another type of allergy to egg, your GP may decide you should be vaccinated with an egg-free vaccine.
- If no egg-free vaccine is available, your GP will identify a suitable vaccine with a low egg (ovalbumin) content, the details of which will be in the Green Book – Immunisation against infectious disease (see NHS Choices).
- Depending on the severity of your egg allergy, your GP may decide to refer you to a specialist for vaccination in hospital.
- If you are ill with a fever, do not have your flu jab until you have fully recovered.

### **How soon after I receive my flu jab will I be immune?**

It takes about 10-14 days after your injection to develop protection against this year's strain of the flu. Protection can last up to one year. The vaccine will not protect against colds and other respiratory illnesses that may be mistaken for influenza but are not caused by the influenza virus.

### **What are the possible side effects of the flu jab?**

The flu jab does not normally cause side effects. Sometimes, it can cause mild fever and slight muscle aches for a day or so. It cannot cause flu as there are no active viruses in the vaccine. However, people sometimes are a little more at risk of catching other flu-like viruses, or very occasionally could catch flu before the vaccine takes effect. Allergic reactions to the vaccine are rare.

### **If you develop symptoms such as a high temperature, fever or chills:**

Drink extra fluids such as water or fruit juice. Take a medication such as paracetamol to help treat headaches and reduce any high temperature. If your symptoms persist and you feel unwell, contact your GP or NHS Direct for further advice.

*If you have a severe allergic reaction (anaphylaxis) including hives, swelling of the face, lips or throat, wheezing and/or shock (fall in blood pressure):*

*Contact the emergency services immediately as you may need to have medication to treat the anaphylactic reaction.*

### **What if I'm allergic to latex?**

There is no latex in the seasonal flu vaccine packaging or in the syringe.

### **Can the flu vaccine be given if I am on other medication?**

Yes. The vaccine can safely be given when you are taking most medications. Discuss this with your doctor or nurse if you are unsure about this.

Rituximab treatment can reduce response to vaccinations. If you are receiving Rituximab you should have your vaccinations one month pre Rituximab or four months after your infusion.

### **Can the flu jab and other vaccines be given at the same time?**

Yes. Flu vaccine can be given at the same time as other vaccines. Pneumococcal vaccine or routine childhood vaccines are often given at the same time as the yearly flu vaccine.

### **If I am currently taking an antiviral medication, is it safe to have the yearly flu jab?**

Yes. It is safe to have the vaccine while taking an antiviral medication.

### **If I am due to have an operation, should I still have the flu jab?**

Although it is safe to receive the flu jab prior to surgery, please check with your surgeon before being immunised to avoid the risk of cancellation of the surgery. Should you experience a side effect (such as a fever) from the influenza vaccine your surgery has the potential for being cancelled.

## Flu Season Advice (continued...)

### **I am pregnant and planning to breastfeed, is it safe and recommended to have the flu jab?**

Yes, all pregnant women should have the flu jab irrespective of whether they have lupus or not. Pregnant women are more at risk of developing the flu and there is evidence that the flu vaccine can be safely given in all stages of pregnancy. The vaccine does not carry risks for either mother or baby and there are some studies that suggest that for some babies, protection from the flu can be passed from mum to baby which lasts for the first few months of life.

### **My child has lupus. Should they have the flu vaccine as an injection or the nasal spray?**

It is advised that children with lupus should have the flu vaccine injection rather than the nasal spray. The injection is an inactive 'dead' form of the flu virus, so it cannot cause an infection. The nasal spray vaccination is an attenuated 'weakened' form of the flu virus which could potentially pose a risk of infection in those with a compromised immune system.



### **Do I need to avoid contact with children who have been immunised with the nasal flu vaccine?**

If you have lupus and have a child who is due to have the nasal flu vaccine, it is advised to speak with the doctor, nurse or pharmacist before vaccination to decide if it is suitable to go ahead.

If you have close contact with a child within two weeks of them receiving the nasal flu spray vaccination you may come into contact with the attenuated (weakened) virus, unless you have been vaccinated at least 14 days prior. It is an added incentive, therefore, for you to have your flu vaccination injection, and preferably early in the season to ensure that you are protected.

*The article has been adapted from the Lupus Courier October 2011 edition, published by Lupus Society of Alberta and from the NHS Choices website.*

NHS Choices [www.nhs.uk](http://www.nhs.uk)

World Health Organisation flu advice <http://www.who.int/topics/influenza/en/>

Department of Health immunisation advice <https://www.gov.uk/government/collections/annual-flu-programme>

## Out and About...



A super snap of John and Lara at Cambridge 105 radio station back in September.

They were interviewed on a new Sunday morning show and discussed the ins and outs of Lupus, from diagnosis, symptoms, treatments, and the role of our Group in offering support.

You can listen again to the interview at

<https://cambridge105.co.uk/sunday-brunch-02-09-2018/>

## Cash for the Community



The Cambridge Building Society gave away over £12,000 to the 15 worthy beneficiaries that made it to the final of this year's Cash for the Community initiative. The local groups and charities were celebrated at a special event held at the Hotel Felix in Cambridge, where it was announced how much of the £12,000 pot each would receive. The Cambridge Building Society teamed up with Cambridge News, for the seventh year in a row, to run the initiative which sees the amount of money donated to each group determined by the number of tokens collected from the paper.



This year 28 groups entered the competition, which was whittled down to the final 15 organisations after a vote by The Cambridge staff and a public vote on social media. Chief Operating Officer, Andy Lucas, hosted the celebration evening to reveal how much money each group would receive. The total amount shared added up to more than £12,000 as The Cambridge decided each group should receive a minimum of £250. Chief Executive Stephen Mitcham presented the cheques alongside Cambridge News editor David Bartlett.

Stephen commented on the initiative and said: "We've been delighted with the response this year; 16 tokens were printed in the Cambridge News over the course of three weeks and supporters collected nearly 6,200 tokens. We've had a huge variety of organisations from the local area enter and it's been lovely to find out about the projects or equipment the money handed over will go towards. We really do hope it helps make a difference!" David Bartlett, Editor of the Cambridge News said: "It was wonderful to be involved once again in this great project with The Cambridge. I am sure that the money being handed out to these 15 groups will be of great benefit to the community. Once again, a wide range of organisations have received funds – another indication of the excellent voluntary and charitable work going on in our community on a daily basis. I'd like to thank our readers for their support and The Cambridge for their generosity".

The largest donation went towards Cambridgeshire Stroke Group, which received over £1,500.

This small charity is run entirely by volunteers for all stroke survivors in Cambridgeshire, to help provide a comprehensive support group for all those, of any age, who have had a stroke or similar injury. The group provides support and a lifeline to its members, helping to transform their lives and speed up recovery after a stroke by gaining independence, establishing new friendships and experiencing new activities. The aim of the group is to provide a meeting place in a friendly caring environment for people who have had a stroke and their families, carers and friends.

Maria Hamilton of Cambridge Stroke Group said "I am so delighted by the amount we have received, we never imagined we would receive such a large donation. 100% of any outside funding that the group receives goes directly towards its members and improving their lives and the services we offer. We would really like to reach as many people as possible but recognise that mobility can be an issue for some members and often transport to and from the group events is a key obstacle. With this donation we'll be able to look into subsidising transport and also expand our programme of activities for our service users too".

Another group which received a large donation was Cambridge City Ladies and Girls Football Club, which provides the local community with a football club that offers sporting opportunities for ladies and girls within the local area. The club receives no central funding or grants and is continually having to generate its own funds. The group took home £1,366 and this will help tremendously in providing the club with much needed equipment and where necessary, pitch hire. The third largest slice of funding was donated to Camsight, which brings visually impaired children and families together and supports older people with sight loss to remain a valued part of their communities, ensuring they have the information, support and technology they need to remain independent.

Each of the 15 finalists received the following amounts:

Cambridge Stroke Group - £1,584; Cambridge City Ladies and Girls Football Club - £1,366; Camsight - £1,298; Little Miracles Ely - £1,136; Langdon House - £1,034; Spectrum - £981 Eddies - £791; Motor Neurone Disease Association Cambridgeshire Branch - £737; Cambridgeshire Lupus Group £709; Time to Talk UK - £468; Centre 33 - £455; Home-Start Cambridgeshire - £450; Kidney Cancer UK - £403; STARS Children's Bereavement Charity - £399; SERV Suffolk and Cambridgeshire - £250.



## News and Research



We congratulate Dr. Betty Diamond of Feinstein Institute for Medical Research for her recently published work showing that ACE inhibitors, a specific type of hypertension drugs approved for lowering high blood pressure may prevent memory loss for people with lupus. With her 2018 [Lupus Insight Prize](#) from the Lupus Research Alliance, Dr. Diamond will build upon this work in mice to specifically measure the ability to remember the location of objects and to measure whether ACE inhibitors change the activity of particular genes in the immune system cells in the brain known as microglia.

Following is an excerpt from the [press release](#) issued by Feinstein Institute for Medical Research reporting Dr. Diamond's publication:

The Feinstein Institute for Medical Research researchers published data yesterday in the [Journal of Experimental Medicine](#) that shows the class of drugs commonly used to treat hypertension, ACE inhibitors, can block cognitive decline in mice and might therefore be used to preserve the memory of patients living with lupus.

Lupus is a complex autoimmune disease that arises when the body starts to make antibodies that target its own, healthy cells, often specifically recognizing DNA. Patients can suffer a wide variety of symptoms, but as many as 90 percent develop neuropsychiatric lupus, which is often characterized by cognitive impairments such as memory loss or confusion.

After discovering that the activation of brain cells called microglia likely contributes to the memory loss and other cognitive impairments suffered by many patients with lupus, Betty Diamond, MD, and other Feinstein Institute colleagues wanted to find a way to block microglia. ACE inhibitors are known to block the activation of microglia. In their study with mice, Diamond and colleagues found that the ACE inhibitor captopril protected neurons against activated microglia, preserving their function and the cognitive performance of the mice

### Lupus Isn't Only a "Women's Disease": Coping Tips for Men with Lupus

Did you know that males can get [lupus](#) too? While it's a fact that lupus affects women 9 times more than men, according to research lupus is more aggressive in males than women. One aspect that should not be overlooked is how to cope with this condition, especially one that's been long characterized as a "women's disease," which can feel additionally isolating and stigmatizing and can become a barrier to seeking medical care or support.

#### **The Psychosocial Impact on Males with Lupus:**

A pilot study\* conducted with a group of male lupus patients demonstrated that participants of the study were frustrated and depressed with the unpredictability and invisibility of lupus. The majority of participants reported emotional distress related to the inability or limited ability to work and/or perform physically intense labor. This was also tied to their thoughts about social expectations of masculinity. One participant said, "Pain is weakness." Male lupus patients also expressed a desire to be connected with other male patients for support, education and a sense of identity. Additionally, many of them had not met other male patients with lupus, which they expressed often left them feeling vulnerable and alone in coping with this illness.

#### **Support for Men with Lupus**



**Priscilla Toral**

Communication is a vital part of coping with the many challenges you may face as a male with lupus. Being aware of what you need and how to ask for support and resources is important to living a healthy life with lupus. Here are some helpful suggestions that may provide help for those looking for support:

- Lupus does not define you or your level of masculinity. Although lupus might make it challenging to engage in rigorous activity, talk with your doctor about your level of ability and decide what activities may be helpful to include in your daily routine. Your doctor may suggest your current activity in moderation or help you to incorporate new activities you may enjoy.
- Communication with your doctor is key to the successful management of your condition. Prepare for your appointments by keeping a log of your symptoms and writing down your questions. Keeping a list of your questions and concerns will help to organize your thoughts, ease concerns related to your condition and ensure you get the most out of your medical visits. Keep important contact information at your fingertips, such as your doctor's office number, pharmacy and insurance information.
- Lupus can be very unpredictable and invisible. You may look fine to others, but may be flaring or feeling very ill. It's important to stay informed and educated regarding your symptoms and how they impact you. This will help you to share appropriate information with your health care team and loved ones to ensure your needs are being met.

Males, it's ok to express the emotional impact that lupus has on your life. Support can come in many forms and often sharing your thoughts with those with similar experiences is helpful. Reach out to your support system, share at your level of comfort and connect with other males. Talking to a mental health provider may also be helpful in your lupus management.

## Addenbrookes - Lupus UK Centre of Excellence



One very hot day in July (we know, that doesn't narrow it down much this summer!), the CLG committee were invited by Addenbrooke's Hospital to attend the Lupus UK Centre of Excellence presentation ceremony.

The years' of hard work by the Lupus and Rheumatology department (and all the associated clinics and support staff) had been recognised by Lupus UK. After a vigorous and extremely detailed series of interviews, inspections and form filling in by all involved parties; Lupus UK were pleased to award Addenbrooke's Hospital the 'Lupus Centre of Excellence' status.

The ceremony took place in the Jubilee Gardens within the campus and was attended by all those who helped play a part in achieving this well deserved accolade.

Professor Graham Hughes (of 'Hughes Syndrome' fame) was the guest of honour. He thanked Dr Jordan for inviting him and gave a very humorous and insightful speech, describing the early days of Lupus diagnosis and research. He briefly outlined the lack of awareness which existed then and is still problematic for many patients and doctors alike today. He praised the tireless efforts of the team at Addenbrooke's for highlighting the importance of timely intervention in lupus diagnosis and treatment, and wished them continued success as the latest centre of excellence.

The Lupus team at Addenbrooke's were pleased to announce a new annual event in memory of Shelagh Cheesman. It was Shelagh who nominated Addenbrooke's for the centre of excellence award and instigated the application process. She played an integral role in helping the hospital achieve (and most importantly prove to Lupus UK) that they met the required high standard.

Dr Frances Hall told us that the clinic staff wanted to provide a memorial to Shelagh, but felt that a plaque on a wall would not do justice to reflect the life of such a wonderful and charismatic person. After much thought, they struck upon the idea of holding an annual lecture in Shelagh's memory. From 2019, all training junior doctors will attend the 'Shelagh Cheesman Memorial Lecture' as part of their rotation. The day will focus on lupus and related autoimmune disorders.

We would like to thank them for this very kind and thoughtful gesture.



**Photos:** 'the presentation party' (top left); Dr Hall (above); Shelagh Cheesman (below); the CLG committee with Shelagh's husband Gary (left).



### Jacky's Kitchen

*I really enjoy Autumn with its warm colours, evenings by the fire and comforting food.*

*These spicy recipes are the perfect accompaniment.*

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

#### **Spicy Lentil and Sweet Potato Chilli:**

*A lovely mild vegetable chilli. Serve with rice, jacket potatoes or quinoa and a lovely green salad.*

Serves 4

1 onion

300g sweet potatoes

1 fresh red pepper

1 400g tin of chopped tomatoes

400ml vegetable stock

1tsp asafoetida

1tsp-2tsp chilli powder according to taste

1tsp ground coriander

1tsp ground cumin

½ tbsp of alternative soy sauce. (I use Cocofina Amino which is coconut based)

200g bag of baby spinach

400g can cooked lentils drained and rinsed

Salt and pepper

Peel and chop the sweet potatoes into small chunks. Cut the red pepper into small pieces leaving out the seeds.

Chop the onion into small pieces and gently fry in a large pan for a few minutes until soft. Add the sweet potatoes, spices, red pepper, cocofina sauce, tomatoes and stock. Season and bring to the boil.

Cover and simmer on a low heat for about an hour until the potatoes are soft. Stir regularly and add more stock if necessary.

Add the lentils and spinach to the chilli and heat through for about another

4 minutes before serving. Season to taste.



#### **Maple and Pecan Nut Cake:**

150g avocado spread or similar vegan margarine/spread plus extra to grease the pan

125g soft brown sugar

250ml Maple syrup

1tsp vanilla extract

2tsp mixed spice

2 tsp chia seeds mixed with 4 tbs spoons of water (stir and leave for 5-10 mins)

300g gluten free flour. (I use sorghum)

1 tsp bicarbonate of soda mixed with 2 tbsp of warm water

## Jacky's Kitchen (continued...)



Preheat the oven to 170°C/325°F/gas mark 3. Grease a small roasting tin or ovenproof dish and line the base if non-stick. Tin size- approx. 20cmx30cm.

Add the maple syrup, margarine spread, vanilla, sugar and mixed spice to a saucepan and heat on a low setting, stirring regularly until melted.

Leave to cool for a minute or two and add the bicarbonate of soda mixture and the chia seed mixture.

Whisk the flour, the melted maple syrup mixture and the nuts together using a mixer or food processor until smooth and glossy and the nuts are small pieces. The batter will be thick but runny.

Pour into the tin and bake for approximately 45 mins until light brown and springy when touched. Allow the cake to cool slightly and cut the cake into

square portions. It should make about 20.

**Notes:** The cake is particularly lovely warm and smells amazing. It will last for about 3-4 days in a sealed tin but if it gets a bit dry I often add a touch of warm maple syrup on top or serve it with coconut cream.

## Donations



The well attended funeral of our long-standing committee member Shirley Smith, took place on a warm and very sunny afternoon on the 27th June. It seemed somewhat fitting for the weather to be as bright and cheerful as Shirley always was. The church in Swavesey was full and Shirley arrived in style in a beautiful horse-drawn carriage. After the service, the funeral cortege made it's way through the village, on route to the crematorium.



The photo (left) has been provided by kind permission of her family. It was the talk of the village as it is such a rare sight to see these days. Shirley would have approved, being passionate about animals and the countryside all her life.

The CLG would like to take this opportunity to thank all of Shirley's family and friends for their extremely kind and generous 'in memoriam' donations to our local Group. We received £812 which we will put to very good use in Shirley's memory. It will help fund the 2020 Information Day; an event Shirley valued.

We would also like to thank Waitrose (Trumpington) for selecting us as one of the three beneficiaries of their 'green token' scheme throughout the month of July. CLG were up against stiff competition with another local charity supporting partially sighted people, who had a photo of a cute puppy on their box! Lara and John went into the store to collect a cheque from the branch manager for a wonderful £284 (photo - right). Thank you to everyone who voted for us.

**Thank You... We are so grateful to all those who have donated and fundraised for us.**

AGM	£528
In Memory of Shelagh Cheesman	£344
Elaine's Hair fashion	£68.81
Cambridge Building Society	£709
In Memory of Shirley Smith	£656
In Memory of Shirley Smith to LUK	£156
Waitrose and Partners	£284
Phil Whiting	£10



# YOUNG WORDS

## THE RAMBLINGS OF A GIRL WITH LUPUS

Well, it's been a while hasn't it? Sorry for the quiet spell! Hoping everyone had a wonderful summer!

I'm pretty sure we can all agree that this summer has been an absolute scorcher, which has come with its ups and downs. I know we're all told to be very careful with the sun, but that doesn't mean that I haven't been moronically, blindly stubborn as per usual and spent as much time out in it as physically possible.

Although it wasn't the sun that caused it, I was very unwell back in June and hospitalised for sepsis (hence my lack of newsletter), which really took its toll on me. It's never fun when you have to cancel plans because you're stuck in an isolated hospital room with nothing to do but watch time pass you by. It left me with a lot of time to think about my life and what I've done and what I hope to carry on doing. Sometimes that meant feeling a little down about perhaps not doing what I would have liked to have done so far, and others it meant looking forward to what I still hope to achieve.

In the years I'm sure I've talked about pacing and planning more times than I've actually talked about having Lupus, so to avoid sounding like a broken record, I'll skip the usual chat about how I obviously did too much this summer and the repercussions of not taking time to rest and recover!

Instead I want to talk about what's ahead. After 6 years, I've finally decided to go ahead and plan to have my hip replaced. In 2012 I found out that the extended treatment of steroids I'd been on had meant I'd developed Avascular Necrosis. Since then I've been hobbling through life on a hip with no cartilage and more damage than I care to think about. It hasn't exactly been easy but the thought of having major bone replacement surgery at 17 was too much to think about, and as stubborn as I always am, I couldn't commit to having it back then.

But last month I hit a point where it was just too much. Unable to walk long distances and always being in pain just became too much. It was a different kind of learning curve, of realising a limit not for just the little things but the big picture. I was out with my sister and a friend and found myself sobbing in public because I was in so much pain, and this wasn't the first time this had happened over this past summer. I finally found my limit, and I will remain proud of how I've handled myself over the last 6 years, but 23 is it, I can't keep it up anymore and it's time to have this surgery.

I had this plan to "hold off until I was 25" because I thought that my big life plan would be playing out just as I imagined and I'd be living some ridiculous, meticulous schedule. That of course, didn't really happen. And for a lot of reasons, I'm really actually quite happy about it. Who I wanted to be at 17 and who I want to be now are very different people. Not that who I wanted to be at 17 was bad, it's just that I've changed and learnt and growing isn't something you can plan.

An element of fear played a bit part in me putting this off, I don't handle myself very well in situations like that and even after 10 years of being sick the hospital still scares me at times. I don't think that I'm necessarily any braver now than I was at 17, the fear is still very much there, it's just time. I have to be okay with being afraid, as my friends and family keep reminding me, it's a pretty damn scary thing and all things considered, I'm allowed to be afraid.

Which is what I've been telling myself a lot recently, and I feel like we could all remind ourselves more often. We are allowed to be afraid, upset, worried, scared. We are allowed to feel a whole bucket load of feelings, we deal with a lot and we are allowed. It doesn't make us any weaker, any less brave or any less worthy of love and support. So to everyone scared and struggling, you've got this and you are doing incredibly.

Until next time,  
Daisy x



### Get well soon

We would just like to offer some 'get well soon vibes' to Daisy, and thank her for managing to contribute to this edition, despite the best efforts of Lupus! We really do appreciate your articles and thoroughly enjoy reading about lupus views from a young perspective. We also send get well soon hugs to one of our committee members, Kate Evans.

To all those in need of a fruit basket, bunch of grapes or a hug over recent months; we wish you speedy recoveries. Remember, our committee contacts are always available to meet up on an ad-hoc basis if you need a chat or support during difficult times. Please feel free to call or email us (contact details on the back cover).



## DIARY DATES

### Peterborough Coffee and Chat

Saturday 20th October 2018.00am - The Restaurant Van Hage Garden Centre Peterborough Garden Park

Contact Jane for details

### St Ives Coffee & Chat

Saturday 3rd November 2018 – 11.00am – St Ives Library St Ives.

Contact Lara or Davina for details

### Cambridge Coffee and Chat

Saturday 7th January 2019 - 11.00am Sunflower Restaurant, Scotsdale's Garden Centre, Great Shelford, Cambridge.

Contact Lara or Davina for details

### Ely Coffee and Chat

Saturday 14th January 2019 - 11.00am - Costa Coffee Ely Leisure Village, Downham Road, Cambridge.

### Peterborough Coffee and Chat

Saturday 21st January 2019. 11.00am - The Restaurant Van Hage Garden Centre Peterborough Garden Park

Contact Jane for details

### St Ives Coffee & Chat

Saturday 2nd February 2019 – 11.00am – St Ives Library St Ives.

Contact Lara or Davina for details

### ON LINE



#### Cambridgeshire Lupus Group

<https://www.facebook.com/Cambridgeshire-Lupus-Group-224656920893520/>



#### Cambs Lupus Group @CambsLupus



#### Cambridgeshire Lupus Group

<http://cambridgeshirelupus.org.uk/>

## Committee & Contacts

Chair & <b>Contact</b>	<b>Davina Frost</b>		<b>Tel: 01954 211679</b>
Vice-Chair	John Webb	Mobile: 07770 451444	Tel: 01480 384433
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Social Secretary	Lara McDonald	62 West Drive, Highfields Caldecote, Cambridge. CB23 7NY	Tel: 01954 210765
Treasurer	Heidi Clark / John Webb	Mobile: 07397 112118	Tel:
Committee and <b>Contacts</b>	<b>Jane Robinson</b>		<b>Tel: 01733 560582</b>
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Committee	Kate Evans	Mobile: 07989 723514	Tel:
	Helen Parish	Mobile: 07917 208040	Tel:
	Sarah Booth		
NewsLetter	Helen Parish / John Webb		

Please use our group email address: [mail@cambridgeshirelupus.org.uk](mailto:mail@cambridgeshirelupus.org.uk) to contact any committee member or our trained contacts.

Please respect the fact that most of your committee and contacts have lupus too; therefore direct your calls between 9am and 8pm.

CAMBRIDGESHIRE  
LUPUS  
GROUP



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