Hello Everyone, I hope you have been able to enjoy the summer without being affected too much. It’s always so nice to see the sunshine and wake up to a bright day!

What’s been happening here in Dorset?.... For World Lupus Day 10 May, we had manned information stands at both Dorchester and Christchurch hospitals, with many people coming to find out more about this less known condition we all have.

The Teas in Wimborne were in full flow over May, July and August and we raised awareness and funds at Poole Carnival in August. (see inside newsletter for more details)

I took part in a gentle exercise program at Christchurch hospital through July and met some really lovely people. Learnt a little about Tai Chi too!!

I attended two National Council meetings in London in May and September, where both Chair persons and Coordinators come together to hear about National events and get information and ideas from each other. Its tiring travelling to London but really worth the effort to feel we are part of a much bigger team of people, raising awareness and supporting one another through what can be quite a debilitating illness.

What’s to come in Dorset?...

Saturday 19 November 11am -12.30pm -
Coffee Morning -Dorford Centre, Dorchester with a talk

Saturday 14 January 11am-12:30pm –
Coffee Time at Haskins Garden Centre, Ferndown, Bournemouth (we will be near the smaller coffee bar and have ‘Dorset Lupus Group’ sign on the table)

If you have any ideas for fundraising or get togethers, I am always open to new ideas!! Don’t forget you can email or ring myself or one of the other contacts if you want a chat or need any information. That’s what we’re here for!

Helen xx
Help Required!

I would really like to organise a large ‘Lunch 4 Lupus’ at a local Hotel in April/ May next year but I need help to put it together!!

If you would like to join me in a small planning group to get this off the ground, please email me helen.bifield@dorsetlupus.com or ring me on 01202 696299.

I need help with ideas plus physical help with setting up and advertising etc - someone good with facebook, twitter knowhow would be great too.

Thank you :)

Lupus Coffee Morning

Saturday 19 November 11am-12:30pm
At The Dorford Centre, Dorchester, DT1 1RR

We will be having a talk about:
‘My Health, My Way’

A free service provided by the NHS to help people manage long term health conditions.

Location: - The Dorford Centre is located next to the Top of Town roundabout in Dorchester.

From Yeovil on the A37, after passing the village of Charminster on your left, you come to a main roundabout which is the northern end of the Dorchester bypass. Take the first turning off the roundabout and you will soon come to a hill with flats on your right, take the third exit on the roundabout at the top of this hill and we are on your left.

From Poole on the A35, after driving over Yellowham Hill on dual carriageway you will eventually come to a roundabout. Take the third exit towards Dorchester and continue straight through the town, passing the Corn Exchange on your right, until you arrive at a roundabout where you will see the Dorford Centre ahead and to your left.

From Weymouth on the A354, continue over the Tesco roundabout and straight on until you come to the traffic lights beyond the railway bridge. Turn left and go straight on at the next set of lights, with the Borough Gardens on your right. When you come to the Top of Town roundabout, turn left.

From Bridport on the A35, take the second exit on the Monkey Jump roundabout and follow signs through the Poundbury development to the town centre along Bridport Road, passing the County Hospital on your right. After a short distance, and just before a roundabout, you will see the Dorford Centre on your right.

There is very limited parking on site the nearest public car park is virtually opposite the Dorford Centre. Alternatively, there is the ‘park and ride’ service.
Report on the Lupus Interactive Education Morning

Firstly, I would like to give a HUGE thank you to Carol Brumpton our Lupus Nurse, for putting this third education morning together on Friday 7th October. We had a super meeting at Christchurch in the larger Macmillan Seminar room, 30 people attended, we had two brilliant talks, firstly from Dr Marks on treatments (see notes below) and after our coffee and cake (yes Cakes…) Lupus UK CEO Chris Maker spoke on the valuable work at both Head Office and around the UK, stressing the benefits of the growing number of Lupus Nurse Specialists now being funded for 5 years by Lupus UK.

Dr Johnathan Marks gave an informative talk to the group on treatments for Lupus both old and new. Below are Dr Marks notes from his talk, he would like to stress however, not to stop or change any medication without discussing your situation or concerns with your specialist.

WHAT'S OLD AND WHAT'S NEW IN THE TREATMENT OF LUPUS: Jonathan Marks

HYDROXYCHLOROQUINE (HCQ)

WHAT IS OLD?

- Chloroquine described as being effective for joint pain and fatigue in 1894!
- Most effective for skin, joint and constitutional symptoms such as fatigue
- Eye toxicity remains the big worry for managing patients on long-term HCQ. Risk is low but rises with long-term use:
  - 0.3% in first 5-7 years; 3.1% at 20 years
- Aim for less than 6.5mg/kg (individuals weight in kg)
- Annual eye test
- [http://www.eyedock.com/plaquenil-calcs](http://www.eyedock.com/plaquenil-calcs)

WHAT IS NEW in HCQ?

- PLUS (France have been running trials)
- Lower doses of HCQ associated with more lupus activity
- Higher doses of HCQ associated with less flares
- LUMINA (American trial)
- HCQ associated with lower mortality in ethnic minority groups

WHAT IS THE ANSWER

- Antimalarials (of which Hydroxychloroquine is the drug of choice) remain the cornerstone of treatment for patients with lupus
- Some evidence that early use of HCQ is associated with a better long-term disease prognosis and less heart disease
- May not be as effective in Sjogren’s syndrome as previously thought

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CORTICOSTEROIDS (Prednisolone)

WHAT IS OLD?
- Discovered in 1950s
- Used for lupus and connective tissue diseases for many years
- Often used for flares of disease activity

WHAT IS NEW in Prednisolone?
- Growing link between chronic steroid use and organ damage including heart attacks
- Doses of 5mg or less seem to be safest in terms of side effects and reducing damage
- Increased risk of infection with >10mg / day

WHAT IS THE ANSWER?
- Reducing by 1mg/ day estimated to reduce risk of organ damage by around 3%
- Even for patients with established lupus on steroids for many years should be aiming to reduce +/- stop prednisolone

METHOTREXATE (MTX)

WHAT IS OLD?
- Methotrexate has been used in rheumatic conditions since the 1980s
- earliest trials in lupus published in 1990s
- Used in moderately active lupus or where there is predominant joint involvement

WHAT IS NEW in MTX?
- Surprisingly few trials have been undertaken with MTX in lupus
- In countries where newer drugs are not available it is used very widely with good effect

MYCOPHENOLATE (MMF)

WHATS OLD?
- Well established treatment for kidney transplant patients
- Has been used in lupus for many years now
WHATS NEW in MMF?

• More effective than traditional treatments (cyclophosphamide) for lupus patients with kidney involvement (nephritis) and seems to have less side effects

• Being used across a number of conditions including, vasculitis and scleroderma

AZATHIOPRINE (AZA)

WHATS OLD?

• Azathioprine has been used for many years in lupus (1975)

• Again, surprisingly few research trials have been undertaken to prove it is effective

• Useful for skin and blood manifestations and safe in pregnancy

WHATS NEW in AZA?

• Patients on AZA may be twice as likely to develop some forms of skin cancer (nonmelanoma)

• Difficult to be sure what contribution lupus has to this risk

NEW TREATMENTS TO COME....

BIOLOGICAL THERAPIES

RITUXIMAB

• Widely used in treating blood cancers such as lymphoma and well established in treating rheumatoid arthritis

• Used ‘off-label’ in lupus for over 10 years though research trials have not supported its use.

• Seems most effective for joint and blood manifestations

• Effective in patients with active kidney disease

• Expert opinion very strongly in favour of use in severe refractory disease

BELIMUMAB

• First new medication to be licensed for 30 years in lupus

• Shown in trials to reduce disease activity and disease flares in patients with severe active disease

• Trials excluded certain lupus populations (brain and kidney involvement)

• Apparently used by 5-6% of lupus patients in the USA
BLISIBIMOD

- Targets BLyS (same as belimumab)
- Seems to be most effective in patients with most active disease
- Trial results expected in 2017

CONCLUSIONS

- There are new medications
- We are still learning how best to use the old medications
- Use of newer agents is always going to be limited by cost

Dorset Assistance Fund

Dorset lupus currently holds a small Trust fund to help any members financially. This money can be allocated for any reasonable need. If you are having problems then please feel free to apply by contacting Helen Bifield who will pass your details to Lupus UK CEO Chris Maker who is responsible for the allocation of this fund.

At a previous AGM members identified that many did not qualify for free prescription and that with many GP practices now only prescribing medications monthly, cost was becoming a problem. This is example of how this fund may be able to help with prepaid certificates. A yearly prepaid certificate costs £104 this would allow you unlimited prescriptions for that year. We appreciate that finding the upfront payment for this may be difficult so do contact us to see if we can help. Strict confidentiality will be followed at all times.

Fundraising

Shirley is hoping to arrange another sponsored swim in the new year but more swimmers are needed - would you or family member like to take part and help raise funds for Lupus?

It will be in the form of a relay swim with each swimmer doing 2 lengths at a time.

Please contact me by email spmerrett@ntlworld if you are or know someone who might be interested.
September Lupus UK Press Release

Selena Gomez News Coverage Reveals Lack of Awareness for Lupus in the UK

Selena Gomez made headlines last week by ending her world tour early to focus on maintaining her health and happiness. The 24-year-old revealed a year ago that she had undergone chemotherapy to treat the chronic disease lupus, where the body’s immune system attacks healthy tissue. She told fans she is struggling with lupus-related panic attacks and depression.

Google trends revealed that many people are not aware of the disease and its complications. There was a greater than 1000 per cent spike in Google searches for ‘what is lupus’ in the hours after Gomez’s announcement on Wednesday.

Earlier this year one of the largest global surveys looking at awareness of lupus among the general public was conducted. Key findings in the UK included:

- More than a quarter of respondents (26%) admitted they did not know lupus is a disease.
- More than half of respondents (51%) could not identify or did not know that lupus can result in serious health complications, such as kidney failure, anaemia or a heart attack.
- More than a third of respondents (42%) indicated they did not know any factors that may contribute to someone developing the disease.

“This has demonstrated how low public awareness of lupus is in the UK,” said Chris Maker, CEO of LUPUS UK*. “Low awareness of lupus contributes to the significant delays in diagnosis that we observe of this chronic and potentially life-threatening disease – an average of 7.5 years from the onset of symptoms. It also places an additional boundary between people living with the incurable disease and their families, friends, and others who do not realise the many ways lupus can affect a person.”

October is Lupus Awareness Month in the UK. It is an important opportunity to raise awareness of the disease amongst the public and medical profession as well as improving the understanding of the impact that lupus can have. In 2016 LUPUS UK are aiming to highlight that lupus is often an ‘invisible illness’, making it harder for friends, family and colleagues to understand the impact that this serious and potentially life-threatening condition can have for people living with it.

About Lupus

Lupus is an illness of the immune system, a condition in which the body’s defence mechanism begins to attack itself through an excess of antibodies in the blood stream, causing inflammation and damage in the joints, muscles and other organs. Lupus is a highly variable disease affecting individuals differently. 90% of lupus patients are female but it can also affect men and young children.

About the Survey

The Survey was conducted by GSK and the results were shared as part of GSK’s ongoing efforts to assist the World Lupus Federation to raise global awareness of lupus. The online, six-question survey was carried out under subcontract by Yolo Communications, an international market research and social media insight agency between March 24th and April 8th 2016. The survey involved 16,911 adults 18+ from 16 nations: Argentina, Australia, Brazil, Canada, Denmark, Finland, France, Germany, Indonesia, Italy, Japan, Spain, South Korea, Switzerland, UK and USA (minimum of 1,000 respondents from each nation).
Public Consultation

Are you aware that your local NHS has made proposals to change how and where services are to be provided. Currently there is a chance to have your say about changes to the hospitals. Proposals include changes to A&E; Maternity and Paediatrics from Poole Hospital relocating to Bournemouth Hospital.

To find out what these changes are go to dorsetvision.nhs.uk or to have your say go to involve@dorsetccg.nhs.uk

Next on the agenda are changes to Primary Care with possible proposals to reduce the number of GP surgeries and develop larger Health Centres. Again keep a look out from press and other sources to ensure you have your say.

Thank You for Fundraising

Our grateful thanks to our fabulous fundraisers:-

Debbie Steel along with her amazing team of helpers have raised an outstanding amount of £1031.10 this year, covering six days of serving teas and raising awareness of Lupus at the National Garden Scheme open garden at Hampreston. Thank to everyone who got involved in the washing up, pouring tea, collecting trays and raising awareness of Lupus.

Thanks also to Shirley Merrett and her family for putting together the tombola at Poole Carnival in August, we had a lot of fun and raised £312 for lupus.
Flu Jab Season

Flu season is upon us once again. A few questions answered…..

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.

Will the flu vaccine flare my lupus?
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.

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.

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.

Article taken from Lupus UK