

Dates For



FEBRUARY 2001

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a branch of

"Caring for people with the
immune system illness lupus"

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While I am writing this the sun is blazing through the window and I feel excited at the thought of Spring being just around the corner. It always makes me feel happier to have a bright day and see a few crocuses and snowdrops have braved the day adding to the garden.

At our last committee meeting we were very pleased to see that our membership numbers are increasing. If you haven't renewed your membership please send your £6.00 direct to Ian Brittain, our treasurer and membership secretary. If you cannot locate your form which came with the last issue of News and Views, just send your subscription to him and he will do the paperwork for you.

It is nearly time for our AGM. We are trying to make this a good evening so do make the effort to come along. We also have some Saturday coffee mornings arranged where members, friends and families can drop in for a chat and some refreshment. If you have any concerns there is always a listening ear at these sessions and many friendly faces. If you've not come before do try to make one of the dates.

During this years National Lupus Awareness Week April 9th -13th Kathleen Sanders is having a Lupus information stand in the Dolphin Centre Poole. If you

could help her please give her a ring on 01202 740039

Margaret Hosking

(E-mail: mchosking@aol.com)

NEW MEMBERS

Welcome to any new members. We hope that you will find belonging to Dorset Lupus a valuable and happy experience. We strive to understand Lupus and help each other to learn to live with it more easily. We also raise funds which help with the running of the Lupus Association and enable them to give grants for research projects.

Do try to come along to one of our meetings. You will find that they are very relaxed and happy events. Bring friends and family too if you wish – lots do!

CONTACTS

In the panel on the left of this page you will find a list of Contacts for our group. These are friendly, helpful and under-standing people who have offered their time to chat to anyone about Lupus. There are times when you may need some information and times when you feel a chat may help you. There is no need to sit at home and worry. Just pick up the phone.

UPCOMING EVENTS COFFEE MORNING

**Saturday 24 February
10.30 am - 12.00
The Howard Centre,
Christchurch Hospital,
Fairmile Road, Christchurch**

Our next coffee morning is **THIS SATURDAY**. This coffee morning gives an opportunity to drop

Your Diary

Coffee Mornings

Christchurch - Sat 24 Feb

Westbourne - Sat 24 Mar

Portland - Sat 21 Apr

Evening Meeting

Westbourne - Fri 6 Apr

Lupus Awareness Week

9 - 13 April

in, enjoy an informal chat over a cuppa, and meet new friends and members.

We look forward to welcoming lots of you at this event as usual.

The venue for this one is Christchurch - very easy for anyone living over in the east of our area and also easy to reach from the main Ringwood - Bournemouth 'Wessex Way' dual carriageway.

See enclosed map for directions. If you have any transport problems please contact one of the committee or perhaps another member.

COFFEE MORNING

**Saturday 24 March
10.30am - 12.00
Westbourne Centre,
Alumhurst Road,
Westbourne, Bournemouth**

Next month, our coffee morning is at the familiar Westbourne venue. Very handy for a shopping trip afterwards!

See you there, I hope.

Evening MEETING & A.G.M.

**Friday 6 April
7.30 pm - 9.00 pm
Westbourne Centre,
Alumhurst Road,
Westbourne, Bournemouth**

The AGM is only a small part of this. As those of you who have been before know, the main business of the evening will be meeting friends and having a chat over a cuppa, as usual. We will also try to arrange an interesting speaker, but I have no details at the time of printing.

COFFEE MORNING

**Saturday 15 April,
10.30 am - 12.00
Easton Methodist Church,
Easton, Portland**

Mrs Otter arranges fantastic coffee mornings with stalls to purchase goods, refreshments and a very friendly atmosphere to chat, make new friends, and help with our fund-raising efforts along the way. And to cap it all the location is one of Dorset's most dramatic spots with wonderful views from the Bill out across the sea and along the Dorset coast in either direction. This is an opportunity for a wonderful morning or day out – not to be missed!

Directions: From Weymouth, follow the road signs out to Portland Bill across the causeway beside Chesil Beach. The road then climbs up a hill onto the top of the Bill, and Easton is the first place you come to, about a mile further on.

LIBRARY

Helen Bifield is our librarian and has a good stock of books and leaflets about many aspects of lupus. If you would like to find out more about this service please phone her on 01202 382269

MILLENNIUM YEAR 2000 MEMBERSHIP

Our National Millennium Challenge was to sign up 2000 New Members in the Year 2000 - not just lupus sufferers but family, friends, colleagues etc. willing to support our work. We have indeed signed up a few new members locally, but recently a

lupus sufferer was met who hadn't heard of our Group so we must work even harder to make local people aware of our existence. If you know anywhere that an advertising leaflet could be placed, we have plenty.

FUND RAISING

Congratulations to Debbie White, one of our Christchurch members, who walked the Inca Trail and raised funds for Lupus. This was as awesome trek for someone with lupus. Debbie has written us an account of her heroic effort :-

"Last July, during my 3 weeks holiday exploring Peru, I undertook to walk the Inca trail and, as I am a sufferer of Lupus, I felt that this would be a good opportunity to raise some money for the cause. The trail was a 55km through the Andes mountains and took 3 days to complete. With altitudes of up to 4200m above sea level, the climb was often strenuous but the magnificent views made it all worthwhile. It started near Cusco, the capital of the Inca Empire, and culminated at the Lost City of Machu Picchu. The highlight of the journey would have to be climbing the last 20 - 30 steps up to the Sun Gate to look down over the city, nestled amongst the mountain peaks!

I managed to raise £370 from the friends and family, which was then matched by my employers Abbey National PLC."

Debbie White

Last time I wrote a newsletter, our Vice Chairman Kathleen Sanders was about to do a daring feat! She was intending to abseil down the tower at Tower Park, Poole to raise funds for Dorset Lupus. She has survived and written an account of her experience for us :-

MY MADCAP DAY

One morning I had a telephone call from Skyline Promotions, asking if I would like to abseil 100ft. Down the Tower Park water tower and raise some money for Lupus. Of course my mind went into over-drive, and I thought what a wonderful way of bringing Lupus into the limelight and raise some money. I readily agreed, typical Gemini in me, jump in feet first, closely followed by my head trying to talk some sense into this 70 year old. My dear daughter, Helen, who is petrified of heights, volunteered to abseil with me. The ensuing publicity from the Echo and my interview on Radio Solent soon had another five volunteers, so we were now a team of seven.

The day arrived, Sunday 15th October (I should have been in church). The Echo photo-grapher was already in attendance. We were fitted out with harness, helmet and gloves and given some training. At 10am on this beautiful warm and sunny day, we went inside the tower, what a daunting experience as we faced this extremely steep staircase, there were 10 platforms and must have been 100 stairs. Will my poor knees last out ...

but event-ually we reached the top. "Next one" called the young man, it was my turn. "Face me" he said and attached the rope to my harness. "Walk backwards, legs apart shoulder width, keep walking backwards" all these instructions.

Suddenly I realised that there was no more platform, just empty space and I was over the side. My supporters of family, Lupus members and friends and a huge crowd were below holding their breath. I think I gave them a shock when I slipped, quite safe though as I let my rope out slowly as instructed. It was over very quickly. I was greeted with much applause, hugs and kisses. What a thrilling exhilarating experience.

My sponsor money is still coming in, and to date I think it totals £800, but also Lupus is known to a few more people, and this is important to me. Perhaps I will try a parachute jump next, it certainly appeals to me. I have already gathered the relevant information.

Kathleen Sanders

LONDON MARATHON

Mary Hosking is running for Dorset Lupus in this year's London Marathon on 22 April.

Not only does her mother suffer from Lupus but her brother has recently been diagnosed with Lupus too. She is running to generate sponsorship for our cause.

She needs as many sponsors as possible, so if you could give some money, however small, Lupus UK will benefit greatly. It

will be wonderful if Dorset Lupus can raise a good amount in this event. Please make cheques payable to Dorset Lupus and send to Mary Hosking, 17, Minster View, Wimborne Dorset BH21 1BA

QUIZ RESULTS

There was a good response to our **Sweetie Quiz** and several people managed to get all the questions correct. The winning entry was drawn out of a hat at the Christmas party and was Christine Brittain. Well done Christine.

I am sure those who entered would like to see the answers so here they are (*over the page...*)

1. Tic-Tacs, 2. Bullseye, 3. Mars bar, 4. Dolly Mixture, 5. Marathon, 6. Liquorice Allsorts, 7. Twix, 8. Wine Gums, 9. Milk Tray, 10. Smarties, 11. Aniseed Balls, 12. Polo, 13. Blackpool Rock, 14. All Gold, 15. After Eights, 16. Buttons, 17. Bounty, 18. Gob Stoppers, 19. Mint Imperials, 20. Humbug, 21. Milky Way, 22. Galaxy, 23. Quality Street, 24. Pear Drops, 25. Black Magic, 26. Jelly Babies.

FEATURE ARTICLE

I took this from an **American** website at www.internet-plaza.net/lupus/lupusfaq.html

There are more Questions & Answers on the site than this - I shall continue in the next issue ...

COMMONLY ASKED QUESTIONS ABOUT LUPUS

1. What is lupus?

Lupus is a chronic (long-lasting) auto-immune disease where the

immune system, for unknown reasons, becomes hyperactive and attacks normal tissue. This attack results in inflammation and brings about symptoms.

What does auto-immune mean?

Literally it means immune activity directed against the self. The immune system fights the body itself (Auto=self). In auto-immune diseases, the immune system makes a mistake and reacts to the body's own tissues.

What is inflammation?

Literally it means setting on fire. It is a protective process our body uses when tissues are injured. Inflammation helps to eliminate a foreign body or organism (virus, bacteria) and prevent further injury. Signs of inflammation include; swelling, redness, pain and warmth. If the signs of inflammation are long-lasting, as they can be in lupus, then damage to the tissues can occur and normal function is impaired. This is why the treatment of lupus is aimed at reducing the inflammation.

2. Are there different kinds of lupus?

There are three forms of lupus including:

Cutaneous lupus (sometimes called Discoid) affects the skin.

Systemic lupus attacks multiple systems in the body which may include: the skin, joints, lungs, blood, blood vessels, heart, kidneys, liver, brain and the nervous system.

How is cutaneous lupus diagnosed?

Cutaneous lupus, because of the great deal of variability in the way that the skin rashes may appear, can be quite difficult to diagnose. However, a skin biopsy may be performed and this may be diagnostic.

What kind of Doctor specializes in cutaneous lupus?

Drug-induced lupus may develop after taking certain prescription medications. Symptoms generally disappear, within weeks to months, after the drug is discontinued.

Neonatal lupus, a fourth type, is a rare condition. It is not the same thing as SLE.

3. What are the symptoms of cutaneous (or discoid) lupus?

The symptoms of cutaneous lupus may include a variety of different looking skin rashes, photosensitivity (where exposure to ultra-violet light triggers a rash), and sometimes ulcers on the inside of the nose or mouth.

What do the rashes look like?

There are a variety of ways that cutaneous lupus rashes can appear. The distinctive rash is called the "butterfly rash," which is a rash that extends across the cheeks of the face and the bridge of the nose. It can be flat or raised; it can be bright red or it can be just a mild blushing, light pink coloration to the skin. It appears on the face in a pattern that looks like a butterfly; the wings are beneath both eyes and the body of the butterfly covers the bridge of the nose.

Another classic rash found in cutaneous lupus is the discoid rash. This rash is coin-shaped or oval in shape, like a disk and it is seen on areas of the skin that are exposed to sunlight. Discoid lesions (sores) tend to be red and raised and become scaly. When they heal they can leave behind a

A Dermatologist specializes in diseases of the skin, hair and nails. Cutaneous lupus is one of hundreds of diseases that involve these areas.

How is cutaneous lupus treated?

Treatment of cutaneous lupus may include corticosteroid creams or ointments applied to the rash or lesions. If the lesion does not respond to cream or

scar. These rashes can also result in a change in coloring of the skin, making the area around the lesion either lighter or darker in color. These Discoid lesions may appear on the scalp; they may appear on the face in a butterfly distribution; they may also appear, as mentioned earlier, in areas where the skin receives sun exposure. Especially, for example, the V of the neck.

Another type of lupus skin rash is classified as the subacute cutaneous lesions. These are lesions characterized by redness. They are also coin-shaped, very photosensitive and they get worse when exposed to ultra-violet light. These are lesions that do not leave behind scars, and can appear over large areas of the body. People who have subacute cutaneous lupus erythematosus (SCLE-a subset of cutaneous lupus) may experience systemic symptoms such as muscle and joint pain, fever and general discomfort. Serious kidney or nervous system problems are rare.

These are just a few examples of what cutaneous lupus rashes may look like. Because the appearance of skin rashes in lupus can be quite variable, it can be difficult to diagnose just by looking at the lesion, and therefore other tests may be necessary.

ointment, the doctor may prescribe injections of corticosteroids directly into the lesion. If a person has particularly wide-spread lesions, oral corticosteroid medications may be prescribed or the doctor may prescribe anti-malarial medications such as Plaquenil (hydroxychloroquine).

In addition to these medications, sunscreens are an important part

of the prevention of photo-sensitivity (where skin exposed to ultra-violet light reacts by developing a rash) reactions that may occur with cutaneous lupus lesions.

4. I have hair loss due to several scars on my scalp, all are about the size of silver dollars. Is there anything to help this kind of hair loss?

If biopsy results indicate advanced scarring on the scalp, then there is little chance of bringing back significant amounts of hair. If, on the other hand, scarring is not prevalent, then treatment with corticosteroid and/or antimalarial drugs may be successful in getting the hair to return. When the disease is inactive, hair usually grows back.

Will the drugs used to treat baldness help the hair loss due to lupus?

Suppressing the disease with medication helps hair to regrow.

5. Is there anything that can be done to cover the lesions (sores) that show-up on my face?

There are some commercially available make-ups. Covermark make-up is a type of make-up that's available that may be helpful in this situation.

6. Can lupus cause either hives or a sensation of burning in the skin?

Lupus may cause hives. Itching can also occur but this is not a

Should people diagnosed with SLE or Cutaneous lupus avoid taking the drugs associated with drug-induced Lupus?

Most of the drugs associated with DIL can be safely used in people with SLE or cutaneous lupus if there are no suitable alternatives.

How soon after taking the drug do the symptoms appear?

Drug-induced lupus requires months to years of frequent exposure to a drug before

common finding. The sensation of itching is due to irritation of nerve fibers in the skin. If the irritation is more intense, it may cause a burning sensation.

7. How is cutaneous lupus different from systemic lupus?

Cutaneous lupus is confined to the skin, whereas systemic lupus may involve not only the skin, but any of the other organ systems in the body.

Can cutaneous lupus turn into systemic lupus?

In approximately 10% of the cases of cutaneous lupus, it evolves and develops into systemic lupus. However, this can't be predicted or prevented from happening.

8. What is photosensitivity and what are photosensitivity reactions?

Photosensitivity is sensitivity to the UV (ultra-violet) rays from the sunlight and other UV light sources. Photosensitivity reactions typically include a rash, but may also trigger fever, fatigue, joint pain and other symptoms of SLE. In some cases, sun exposure has resulted in the onset of kidney disease.

9. What is the difference between drug-induced lupus and systemic lupus?

Systemic lupus is irreversible, whereas drug-induced lupus generally is reversible. The symptoms of drug-induced lupus generally DO NOT include:

symptoms appear.

How soon after discontinuing the drug will the symptoms go away?

It varies from days, to weeks, to months. Usually symptoms fade after six months. The ANA may remain positive for years.

10. What causes lupus?

The exact cause of lupus is unknown. It is likely to be due to a combination of factors. For example, a person's genetic

kidney involvement or central nervous system involvement

What drugs are most commonly associated with DIL?

There is just a short list of medications for which there is DEFINITE PROOF of an association with drug induced lupus. The list includes 5 medications:

Procainamide (pro-can-a-mide) brand names Procan or Pronestyl used for heart rhythm abnormalities

Hydralazine (hi-dral-a-zine) brand name Apresoline or Apresazide used for high blood pressure

Isoniazid (i-so-nye-a-zid) brand name INH used for tuberculosis

Quinidine (quin-i-dean) used for heart rhythm abnormalities

Phenytoin, brand name Dilantin used for convulsive disorders (seizures).

Are there other drugs that might cause DIL?

The overwhelming majority of cases of DIL are due to one of the 5 drugs mentioned earlier. There are other drugs which might POSSIBLY be associated, but there is not yet definite proof of an association between them and drug-induced lupus. Check with your doctor to see if you are on any medication that might possibly explain your symptoms.

make-up and exposure to certain unknown trigger factors may provide the right environment in which lupus can develop.

Is it hereditary?

We suspect (but do not have scientific proof) that people inherit something from their parents that predisposes them to develop lupus. They are not necessarily pre-destined to develop lupus, but they may be more susceptible. At the present time, there are no genetic tests to

determine who is susceptible and who is not.

Several researchers are doing Linkage Studies to evaluate families in which more than one member has lupus. They hope to be able to identify a gene or genes that are responsible for lupus.

Undoubtedly the resources of all of these groups will eventually be pooled, but there is much to be gained from the current phase of multiple independent efforts. Participation in multiple studies is encouraged.

Can I have my children tested?

Testing isn't advisable in asymptomatic individuals.

What can trigger lupus?

It is believed that certain things may trigger the onset of lupus or cause lupus to flare. Trigger factors include:

Ultra-violet (UV) light

Certain prescription drugs

Infection

Certain antibiotics

Hormones

Although there is no scientific evidence, it is possible that extreme stress may play a role in triggering lupus.

Is lupus stress related?

We do not know for certain. There are many anecdotal reports (personal accounts) of lupus flaring during or after a stressful time, but this question requires further scientific study.

Are flares related to hormones?

We do not know for sure. There are many reports of lupus flaring with pregnancy, the menstrual cycle, birth control pills, and hormone replacement therapy. We suspect that hormones play a role, but we don't know precisely what the role is. Lupus has a 9:1 female to male ratio so it is likely that hormones play a role, perhaps by influencing the

immune system. Also, we know that female hormones have a definite effect on lupus mice.

Are there any medications people with lupus should avoid?

There are no absolute contraindications to needed and appropriate medications for a person with systemic lupus. Your doctor should watch for allergic reactions to medications, and watch for any connection between flares and estrogen or oral contraceptives.

People with lupus should be especially careful if they are prescribed sulfa antibiotics. These medications (Bactrim, Gantrisin, Septra) are often prescribed for urinary tract infections and may cause an increase in sun sensitivity and occasionally lower blood counts resulting in disease flares.

Does lupus occur more often in certain geographical areas?

No

Is lupus related to pollution or toxic chemicals?

We do not know.

Can something in your diet cause lupus?

We do not believe so.

That's All for the moment ... MORE NEXT TIME

Margaret Hosking