



DORSET LUPUS GROUP NEWSLETTER

SPRING EDITION 2014

CHECK OUT OUR NEW WEBSITE !

**ARE YOU ON FACEBOOK?... JOIN
OUR PAGE AND GET INVOLVED!**



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PATRONS

Christopher Chope OBE MP
and Christo Chope & Dr. Neil
Hopkinson DM FRCP

SPONSORS

If you would like to sponsor
us or know a company who
would, please get in touch.



Spring is in the air...

Hello everyone and welcome
to our Spring Newsletter.

I, for one, am not complain-
ing about how quickly
Spring seems to have
cropped up on us this year,
(although I guess there is still
time for winter to return). As
a keen gardener I cannot
wait to get out there and
start clearing away the de-
bris. My lupus restricts me to
"little and often" so the
longer I have, the better!

How about the rest of you?
What hobbies do you have?
How do you manage coping
with them when your lupus
is bad especially during the
cold and dark evenings?

Following on from the last
Newsletter, I do not think a

Lupus Nurse has been ap-
pointed as yet, although I
believe that things are pro-
gressing well. We are still
hopeful that someone will
either be in post or at least
appointed by the time of our
A.G.M., on **5th April**, so
please come along and meet
the new Lupus Nurse.

Talking of the A.G.M. we are
also expecting all our pa-
trons, Dr Hopkinson and the
Chopes, plus Chris Maker
from Lupus UK. We have
asked them to say a few
words initially, but then the
main reason for bringing
them all along will be to ask
them about what is happen-
ing both locally and national-
ly with the treatment and
care of lupus patients. With

the many new changes within
the NHS I am sure there is
much to tell. So why not come
along to the Holiday Express
Inn, Poole (right next to the Bus
Station) and have your say and
find out more.

As always we shall also be voting
for a new Committee so if you
would like to get involved in any
way, please come along or call
David Mays prior to the meet-
ing, so that we can put your
name forward. New ideas and
opinions are always welcome to
invigorate both the committee
and the Group.

This Saturday, Shirley will be
helping us to relax, something
that I will certainly find invalua-
ble. so why not come and join
in. Hope to see you all there.

Debbie x

EDITORS MESSAGE

Hi everyone.

I cannot believe what a wet
start it has been to the year, it
seems that it has been ongo-
ing for months! I hope every-
one is keeping well and that
the wet, damp weather is not
affecting health issues too
much. More importantly I
hope everyone is safe and the
terrible floods and storms
have not caused too much
damage all round. I feel like I
have been quite sheltered
from it all working from
home most of the time.

But now spring feels like its
approaching, my amaryllis

has just flowered and I keep
seeing snowdrops in between
the hail and rainstorms!!

The coffee and chat meet ups
in the west of the county
have been proving very pop-
ular and Rose Smeeton has
had a wonderful turnout of
people each month. If you
would like to see what its all
about, they meet every 2nd
Tuesday monthly in
Weymouth - see more details
on page 2.

Stay safe, warm and well and
don't forget to check out our
new website! *Tamsin x*

Trust Fund



The Dorset Lupus Group
have a trust fund, with about
£1500 in it, and would like to
be able to use this money to
help our members. Donations
have been from the Dorset
Lions and from the Bourne
Lodge, with the stipulation
that it was to be used for local
sufferers of lupus only.

If anyone would like to speak
to Tamsin confidentially, to
see whether Dorset Lupus
would be able to help, please
call her on 01202 041149 or
write to 4 Hurn Road, Christ-
church, BH23 2TZ Dorset.

Strict confidentiality will be
followed at all times.

A Review of Past Events...

OPEN GARDEN, MANOR FARM NGS, SAT & SUN 22/23 FEB

How lucky were we? No rain or strong wind to speak of! Saturday was by far the best day, with lots of sun and visitors. We learnt from our mistakes last year so served homemade soup and hot chocolate, as well as the customary tea and cakes. The former 2 items helped keep all those visitors' hands warm as they walked around the garden clasping their polystyrene cups. Thank you Ann, Judith, and Barbara for all the delicious soup.

Sunday was colder but Guy & Anne Trehane set us up with our very own tearooms in their "flood cleared" dining room - £289 in all was raised for Lupus UK. A big, big thanks to everyone involved. Now we need volunteers for Sat May 18th.

Please call Debbie if you can help.

NEW YEARS SUNDAY LUNCH JAN 26TH

There was a good turnout for this annual event. The food got mixed reviews but the service and the company, of course, was excellent. Cheers!



CHRISTMAS COFFEE MORNING, SAT DEC 7TH

This was just a chance for members to come along and have a chat, exchange Christmas cards and have a mince pie or two! The Meeting was well attended and everyone had good time. Thank you to everyone who brought along a Raffle prize. We raised £26 from the sale of Raffle tickets.



Future Events...



COFFEE & CHAT AT MERLEY CT CARAVAN PK, MERLEY, WIMBORNE BH21 3AA AT 10.30AM ON MAR 1ST

Shirley Merrett will be talking to us about "Exploring Relaxation Techniques to help Manage your Lupus" Plenty of free parking outside venue. For more details call Debbie or visit our website.



COFFEE & CHAT AT THE OASIS CAFÉ, WEYMOUTH DT3 6PN FROM 10.30AM ON MAR 11TH; APR 8TH;

We shall be meeting on the 2nd Tues each month, for those dates mentioned above. For a May and June date please check the website, in the Dorset Evening Echo or with Rose, to confirm the date and venue first. Rose's contact details are 07866 544764 or 01305 761454 if you require further information.



ANNUAL AGM AT HOLIDAY INN EXPRESS, POOLE BH15 1RZ TO START AT 10.30AM ON APRIL 5TH (SEE PAGE 5)

We shall be joined by our patrons, Dr. Neil Hopkinson, Chris & Christo Chope and Chris Maker (from Lupus UK), plus hopefully our new Lupus Nurse to discuss the changes to patient care within the NHS. We shall also have a brief review of the year and vote for a new Committee. All are welcome so come along with your questions and meet the panel.

Please contact us if you would like transport from the train station.



WORLD LUPUS DAY

MAY 10TH



FUNDRAISING AT MANOR FARM, HAMPRESTON, WIMBORNE, BH21 7LX

SAT MAY 18TH; JUNE 8TH; AUG 3RD
& WED AUG 6TH 2014

We have been asked once again to help Anne & Guy Trehane this year, with serving refreshments when they open their garden to the Public under the "NGS Yellow Book"

Scheme. As well as having great fun, we also manage to raise a considerable amount for research into lupus. We always need helpers so if you can spare some time to help, please give Debbie a call.

COFFEE & CHAT NEAR SHERBORNE, AT MILBORNE PORT ON SAT MAY 24TH 10.30AM



Once again Janet & Paul Heath have invited us to their local Church Hall for an informal Coffee and Chat. It's an opportunity for those members in the north of the County to get together, as well as those in other parts to come along and enjoy the beautiful countryside. As always, family and friends are more than welcome to join us.



BOAT TRIP FROM POOLE QUAY TO WAREHAM ON SAT JUNE 21ST

Due to the tides we are unable to confirm times for this trip but will aim for a late morning departure and fish & chips lunch at Wareham. Details tbc. **PLEASE REGISTER INTEREST**

Sweet or Not...

Artificial Sweeteners are getting Increasingly Bad Press - and for Good Reason ...

Though still recommended by public health agencies and nutritionists, overwhelming evidence proves artificial sweeteners actually promote weight gain and are linked to a higher risk of diabetes, headaches, vision problems, high blood pressure and heart disease...

Despite being promoted for weight loss, foods and beverages with artificial sweeteners have never been proven to help weight loss. In fact, studies that look at this actually find artificial sweeteners promote weight gain.

Research has also demonstrated that aspartame worsens insulin sensitivity to a greater degree than sugar, posing a hidden health threat to diabetics who follow the recommendation to switch to diet drinks to manage their condition

The most comprehensive and longest human study looking at aspartame toxicity found a clear association between aspartame consumption and non-Hodgkin's Lymphoma and leukaemia.

The healthiest and most cost effective choice of beverage is pure filtered tap water.

Source: www.drmercola.com

DIET AND SWEETENED DRINKS INCREASE RISK OF DEPRESSION BY 30%..!!

A research team presenting to the *American Academy of Neurology* has found that drinking sweetened beverages, especially diet drinks(!) is associated with an increased risk of depression in adults.

Source: NaturalNews.com

KEEP IN TOUCH

If you know of anyone who is going through a bad time, in hospital, struggling at home or celebrating a special event, please tell me and I will send a card, on behalf of DLG, to let them know we are thinking of them. My email address is smiley.face@sky.com Alternatively phone me on 01202 535123.

Smiley



Health Watch...

Healthwatch is the new consumer champion for health and social care

We can provide you with information about health and care services in Dorset to help you navigate the system.

We also want you to tell us what's going on in health and care services where you live. We want to hear the good and the bad. We will tell services about your experiences of health and care and hold them to account. We're independent, transparent and accountable and we're powerful - we have the strength of the law and the national influence of Healthwatch England behind us.

We are working on a number of projects including:

- Recruiting Healthwatch Dorset Champion volunteers – if you'd like to help us promote Healthwatch please get in touch
- Producing a dementia awareness video with Bournemouth University and the NHS
- Working with students at local colleges to gather young peoples' feedback on health & care services
- Creating a health & care forum of voluntary sector colleagues across Dorset
- Planning a series of themed listening events for next year to gather feedback from people across Dorset

To find out more and to tell us about your experiences of health and care please have a look on our website www.healthwatchdorset.co.uk find us on Facebook & Twitter @HwatchDorset or give us a ring on Tel: 0300 111 0102. You can also find us at your local Citizen Advice Bureau or write to us free at: Healthwatch Dorset, Freepost H1902, 896 Christchurch Road, Bournemouth BH7 6BR

Your Story

If anyone would like to write in and tell us their Lupus story please email it to me on; tamsin@dorsetlupus.com We would love to hear it - maybe its similar to someone else's!

HealthUnlocked

Connect with LUPUS UK and the people affected by lupus

- See what other people with lupus are doing and thinking
- Answers from people within the lupus community

Tools to help you make choices that are right for you. Join a friendly online community of other Lupus sufferers, write a blog or ask a question - it is totally up to you.

<http://lupusuk.healthunlocked.com>

MedicAlert Foundation...



MedicAlert is the only non-profit registered charity providing a life-saving identification system for individuals with hidden medical conditions and allergies. This takes the form of body worn bracelets or necklets bearing the MedicAlert symbol on the disc and supported by a 24hr emergency telephone service. Each member receives an emblem that is engraved with the wearers main medical condition(s) or vital details, a personal ID number and a 24 hour telephone number that can access their details from anywhere in the world in over 100 languages.

There is an annual fee of £25 for membership plus the cost of bracelet chosen starting from £19.95. Contact MedicAlert on **0800 581420** email: info@medicalert.org.uk or see www.medicalert.org.uk.

Coffee Groups around the county

We are trying to set up some little coffee groups around Dorset to get more members involved who would not usually come to the meetings or who cannot get there for one reason or another. If you would like to meet up with others in your area for a coffee and chat please call Tamsin or Debbie and we will try and get in touch with others near you

Lupus and Depression...



If you have lupus, it's normal to feel sad or down sometimes. After all, lupus may force you to make big adjustments in your life. Lupus can put a strain on your personal relationships, and make it hard to do some of the things you enjoy. All this can take a toll on you emotionally. But feelings of sadness or depression that last more than a few weeks should be evaluated and treated.

People with a chronic illness such as lupus are at higher risk of depression. Studies show that as many as 60% of people with a chronic illness will have depression at some point in their lives.

But don't try to diagnose yourself. Some symptoms of lupus -- loss of energy, difficulty sleeping, fatigue -- can mimic the symptoms of depression. See a doctor, and work together to deal with depression.

Here are 11 steps you can take if you have lupus and think you may have depression.

1. Talk With Your Doctor About Depression and Lupus

Your doctor can assess, diagnose, and help you decide what kind of treatment is best. In most cases, your doctor will suggest a combination of psychotherapy and an antidepressant medication. "Some people find they need an antidepressant to help get them out of a rut," says Helen Grusd, PhD, a clinical psychologist in Los Angeles and past president of the Los Angeles County Psychological Association. "Then once they're feeling better, they can start to do other things on their own to help ease the depression."

2. Aim for Acceptance of Your Lupus Diagnosis

"When you are first diagnosed with lupus, it's natural to move through the stages of grief, from denial to anger and depression," says Grusd. These are all normal feelings. But the key is to not stay too long in any of these

stages. Instead, try to move toward acceptance. "Accepting that you have lupus and then moving on with your life can help with depression," says Grusd. This may mean setting new life goals for yourself and finding new things you can do that you enjoy.

3. Keep Self-Talk Positive, Avoid Negative Self-Talk

Whether we realise it or not, most of us talk to ourselves as we go about our day. And what you say can have a big effect on your mood. "What you tell yourself is more important than what others say about you," says Grusd. "So try to keep your thoughts as positive as you can and beware of slipping into negative self-talk."

For example, if you can't do something because your symptoms are acting up, try not to blame yourself. Instead, remind yourself that you're doing the best you can. Or tell yourself that you'll do the activity another day when you're feeling better.

4. Surround Yourself With Supportive People

Having a strong support network is important when you have any type of chronic illness. "It's important to surround yourself with positive people who are willing to be supportive -- even if this means making some new friends," says Grusd.

You may also consider joining a support group for people with lupus. "It's important to get empathy and be around others who understand what you're going through," says Debra Borys, PhD, a clinical psychologist based in Los Angeles. "A support group can be a great way to find this." If getting out is too difficult, you can even find support groups online.

Seeing a therapist is another way to get support. "It can be really helpful to talk with a professional about your worries and concerns," says Borys. "A therapist can also help you improve your relationships with family and friends."

5. Take One Day at a Time

It can be overwhelming to worry about all the things you need to do. Instead, try to focus on one day at a time. It may help to break up the day into small, manageable pieces. "Every morning, I usually prioritize a few things to get done that day," says Utterback. "And if I can't get through everything on my list, I don't get upset with myself. I just tell myself that I'll get to it eventually."

6. Watch Your Mood Closely

It may be helpful to create an internal barometer of how you're feeling, using the numbers 1 through 10. "If you notice you're starting to head down the scale, don't wait until you're at a 3 or 4 to do something about it," says Grusd. "Instead, try to notice small changes right away and do something to pick yourself up if you start slipping a little bit."

7. Keep a List of Ways to Feel Better

Create a list of things that make you feel good. Some examples may include taking a bubble bath, calling a friend, watching a show or movie that you enjoy, reading, taking a short walk, sitting in your garden, or petting your dog. Keep this list handy and do one of these things if you start to feel down. "Keep in mind that the same activity may not always work, so if one thing doesn't work, try another," says Grusd.

8. Connect With Your Spirituality

If you are religious, this is a great time to reach out to your religious community for support. Depending on your beliefs, it may be helpful to go to your church or temple or simply pray on your own. If getting out is difficult, you can request a home visit from those in your congregation. Or simply ask them to pray for you. "Asking other people to pray for you can be very powerful," says Grusd. "Even if they are people you don't know."

Continued on page 5...

Cont from Page 4 / Depression and Lupus...



9. Be as Active as You Can With Lupus

Staying active can also help your mood. "When you're in pain you may not want to move, but doing just a little bit can really lift your spirits," says Grusd. "It can also be very empowering to feel like you have some control over your illness." Do whatever you can, whether it's a walk around the block, or just into the other room.

Some people with lupus also benefit from taking up an activity such as tai chi, very light yoga, guided imagery, or meditation. "Many people find these types of activities help with depression and may even help improve their physical health," says Borys.

10. Learn All You Can About Lupus

The more you know about lupus, the more involved you can be in your treatment. "Becoming a vocal, assertive patient can give you more of a sense of control over the illness," says Borys. "Feeling empowered will help decrease your risk of depression and anxiety."

Learning about lupus will also help

you know what to expect and how to best take care of yourself. But be sure to use trusted sources. Ask your doctor for a list of reading material or organisations that provide reliable information.

11. Keep Up Healthy Habits While Living With Lupus

To feel your best, both physically and mentally, it's important to eat well and get enough rest. Try to eat a well-balanced diet and aim for at least seven hours of sleep each night. You should also avoid habits that aren't good for your health, such as smoking and drinking alcohol. "Taking care of yourself will foster a good attitude and ultimately help you feel better about yourself," says Borys.

Taken from website www.webmd.com



Weymouth meet ups...



Dorset Lupus Group have been meeting up in the West of the county at a regular drop in coffee morning on the 2nd Tuesday of each month. The current venue is at the Oasis Café, Preston Beach Road, Weymouth.

Rose Smeeton is the meeting contact and has had a lot of interest over the last few months and met some new faces.

"We began our 'Drop In' Tuesday back in October at Costa Coffee in Dorchester. A small article in The Dorset Evening Echo brought several people with a new Lupus diagnosis to the sessions. Each left with many a thank you as well as a handful of leaflets; so we felt we had been of some help to those who dropped by."

"After a careful look at the membership list we saw most members were in Weymouth so after our very successful walk from the Oasis in October we decided that we'd try a new venue in January. Yet another short article in the Echo each month has meant we have met and talked 'Lupus' with some existing members and some new to diagnosis."

We would like to bring more members from West Dorset into our events and get-togethers so would really like to know what event or meeting up you would like in the west of the county? What days are best? What time of day? Do you need to car share to events in the east of the county?

Please get in touch and if you have an email address do let us know so we can keep you informed of future events.

Talk to Rose with your views and ideas!
Rosemary.smeeton2@btinternet.com

Rosemary

ANNUAL AGM

Date: **Saturday 5th April**
 Start: **10.30am**
 Place: **Holiday Inn Express, Walking Field Lane, Poole BH15 1RZ**
 Speaker: **Dr Neil Hopkinson**
PLEASE COME ALONG AND SUPPORT YOUR LOCAL GROUP
IF YOU WOULD LIKE TO STAND FOR COMMITTEE PLEASE CONTACT DAVID MAYS (SECRETARY) on 01202 421834/ d.mays@dorsetlupus.com PRIOR TO THE MEETING.

LEAFLETS & POSTERS

We have got some brightly coloured leaflets for the Dorset Lupus Group – describing a bit about Lupus and symptoms along with details of the committee and our group. We also have some Lupus UK posters with information about the Group for Doctors surgeries, libraries, notice boards etc. If anyone would like a copy for themselves or to give out please get in touch with Gerry or Tamsin and we can arrange to distribute them to you.

Could you put some in your local Doctor's Surgery, library, church or Information Office?

Treasury Activity...

£1750 Weymouth Walk—Just Giving Website and sponsorship collected

£111 Collected at Tarrant Monkton including sale of Lupus Xmas Cards

£97 Total collected at the Xmas Coffee Morning at the Royal Norfolk Hotel, including sale of Lupus goods

£289 Raised from refreshments at Open Garden 22/23 Feb

SHARE YOUR NEWS...

Do you have anything that you would like to share in our newsletter.....photos of events, congratulations...ANYTHING!

Please email it to

Tamsin@dorsetlupus.com

Dates for your Diary



Sat March 1st 2014 Coffee & Chat at Merley Court Caravan Park, Wimborne BH21 3AA at 10.30am with speaker about Relaxation Techniques

Tues March 11th 2014 Coffee & Chat , Oasis Cafe at Bowleaze Coveyway, Weymouth DT3 6PN from 10.30am

**

Sat April 5th 2014 AGM: Holiday Inn Express, Poole BH15 1RZ from 10.30am

Tues April 8th 2014 Coffee & Chat , Oasis Cafe in Weymouth DT3 6PN from 10.30am

**

Sat May 10th 2014 WORLD LUPUS DAY

Sun May 18th 2014 NGS Teas Fundraising at Manor Farm, Hampreston, BH21 7LX. 1-5pm

Sat May 24th 2014 Coffee & Chat St John's Church Hall, Milborne Port, DT9 5AH from 10.30am

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Sun June 8th 2014 NGS Teas Fundraising at Manor Farm, Hampreston, BH21 7LX. 1-5pm

Sat June 21st 2014 Boat Trip from Poole Quay to Wareham details in next Newsletter

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Sun August 3rd & Wed August 6th 2014 NGS Teas Fundraising at Manor Farm, Hampreston, BH21 7LX. 1-5pm

Your Local Committee...

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Shirley Merrett
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Non Committee Members:
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01202 303557 / 07798 804434
carol.berkhauer@hotmail.com

Greeting Cards:
Mrs Yvonne Bartlett
01202 535123
smiley.face@sky.com

Benefits Advice:
Jean Durrant
01258 860565

Lupus UK wristbands

These wristbands are now available from the Lupus UK website to help spread awareness of Lupus featuring logo & website details - price £1.00. Debbie has a supply of these so anyone who would like to get one can save on postage costs by getting them from Debbie!



USED STAMPS?

Many of our members are regularly collecting used postage stamps. Please keep them coming! There is no need to peel them off the envelope - just tear around the stamp carefully (as torn, damaged, incomplete and creased stamps are of no value) and bring them along to the next meeting or send them to Debbie in an envelope.

