



Lupus Latest

from the
Grampian Lupus Group

CHAIRMAN'S MUSING'S

For our Lupus awareness month our intention was to have our display at the Bon Accord Centre, unfortunately due to operational issues this was withdrawn. So sadly, as a group we have been unable to do any awareness this month, I do hope you as individuals have had more luck.

I am delighted however to say that for next October in the awareness month we will be able to have our display in the Dyce ASDA shopping centre in the forecourt, hopefully by then we will have gathered enough volunteers for the day.

Thank you for those who had volunteered hopefully we can use your services next year.

See you at our next lunch!

Best regards,

Jim Fletcher.

GLG Committee Contacts:

Jim Fletcher, Chairman:
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Angela O'Sullivan, Treasurer:
01224 495990

Lesley Jenkins, Newsletter Editor:
cydrdog@hotmail.co.uk

Sarah Hewitt, Webmaster:
info@grampianlupusgroup.co.uk

Committee Volunteers :

I have as yet had no luck gaining a new secretary and as this is being written I was hoping to also secure a Fund Raising Co-ordinator. Please contact me again if you would like to help out with any of these posts .

Angela O'Sullivan on 01224 495990.

Club Treasurer, Angela O' Sullivan and her husband John were on holiday in Toronto recently ... here are some of their holiday snaps !



Restaurant at CN Tower



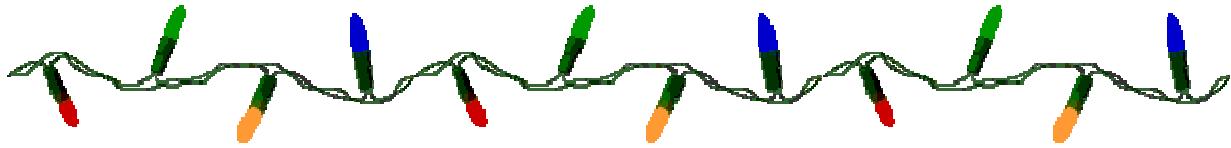
Inside The Bay Shopping Mall



The Royal Park Hotel



At the Toronto Lakes

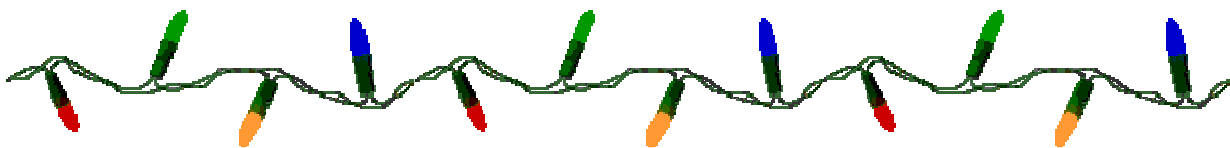


CHRISTMAS LUNCH

Dr Frank Muller, skin specialist will be attending our Christmas Lunch at the Aberdeen Northern Hotel on Sunday November 29th at 12.30 sharp. As usual the lunch will consist of a carvery and sweet at £10.00 per person which is non refundable.

Can we ask that if for any reason you can't make it on the day please call Angela no later than **11.30** on the morning of the Lunch (**29.11.2009**) to let her know so she can pass this onto the hotel, so there are no delay's in serving lunch.

Please complete the acknowledgment which is attached at the **end of the newsletter** and return to Angela O'Sullivan no later than Thursday 26.11.2009, with your money. All cheques made payable to **GRAMPIAN LUPUS GROUP**.





Lupus UK Website

There has been a change to Lupus UK's website in recent weeks. Please take a look at the new updated version.

You will also be able to order any of your Christmas cards and any books that are available for sale on line.

The old GP guide has been updated and would be a useful addition to your Lupus library, see book cover below:



Lupus - Diagnosis and Treatment

**Price:
£5.00**

Grampian Lupus Group Website

We are currently in the process of updating our website.

If you have any stories, articles, photographs or points of view you'd like to add to the site please contact our Webmaster Sarah with your suggestions at:

info@grampianlupusgroup.co.uk

Connective Tissue Clinic

Angela recently contacted Dr Youssef regarding the departure of Nurse Specialist, **Liz Wyber** and the implications that this would have to the clinic.

The following is the response from Dr Youssef :

"Liz's sudden departure has certainly affected the CT Clinic in various aspects.

You will be aware that she was the main educator and a useful point of contact acting as a link between me and my patients.

It looks though that it is likely to be a while before NHS Grampian are in a position to replace Liz and I am hoping that the bid for a Lupus Nurse that we all submitted to Lupus UK (Aberdeen, Dundee, Fyfe and Edinburgh) goes through all right. I am aware that Lupus UK have approved but the logistics will take a while before a suitable applicant(s) is in post. I am one of the co-applicants for this project and was recently discussing in our SLEx meeting the way forward on bringing nursing expertise to Grampian.

This is different from Liz's replacement which will be taken further by NHS Grampian. "

Angela has confirmed that you can still contact Liz's colleague Rena Sandison on: 01224 555 403 for any help. However, this will be for limited information and help only.



Lupus Lunch – 3rd August 2009

Our lunch was again well attended and thoroughly enjoyed by everyone.

Our speaker was **Lesley Davidson**, Senior Physiotherapist, NHS Grampian, who gave an excellent presentation and here are the main points from her talk :

LUPUS & Physiotherapy

Lesley advised that Physiotherapists are aware of the variety of symptoms a Lupus patient has. The symptoms that are treated by physiotherapists include:

Joints and Muscles

- Pain and stiffness
- Joint hypermobility

Fatigue

EXERCISE Is good for you

- Helps keep your joints and muscles flexible
- Helps relieve pain
- Improves the strength of muscles
- Increases your energy levels
- Makes you feel good

JOINT HYPERMOBILITY

- Flexible joints
- Joint and muscle aches / pains
- Physiotherapy
 1. Advice
 2. Exercise
 3. Posture
 4. Pacing

FATIGUE

- **Very common in SLE**
- Affects
 1. Day to day activities – work and leisure
 2. Pain levels
 3. Sleep Pattern
 4. General fitness / activity levels
 5. Mood
- Overwhelming
 - Too tired to do what you want to do

- Vicious Circle
Tired → don't feel like exercising → don't exercise → feel tired and lethargic.
- Inactivity → de-conditioned muscles and reduced fitness
- **What has Found to be Helpful :**
- **Moderate intensity aerobic exercise**
 - Enough exercise to make you slightly out of breath and strengthen your muscles without overworking or exhausting them.
- **Pacing**
Breaking down big activities into smaller manageable steps
- **Relaxation**
Helps your body recharge itself and can improve your sleeping pattern

PACING & RELAXATION

- Balance activity with rest
- Spread activities through the week
- Plan your day – prioritise
- Don't do things you don't need to
- Repetitive tasks - take regular breaks
- Learn to relax – body and mind

EXERCISE – Where to start

- Start at a level that is comfortable to you
- Work at your own pace
- Choose an activity that you enjoy
- Build up gradually to 30 minutes 3 to 4 times a week
- Keep a diary focus on what you can do i.e Stretching, strengthening

HOWEVER.....

THE GOOD NEWS is

Shopping can be exercise too !!!!



Here are the Group at the end of lunch

That's all for now Folks If you have any articles or photographs for the next newsletter please get in touch with Lesley at:

cydrdog@hotmail.co.uk

Hope to see you all on the 29th November.....
Until then *Au Revoir* from the Committee

PS :

Also attached this month is a copy of the Lupus EUROPE newsletter, a report on a recent reception at 10 Downing Street for Lupus Awareness Month and the What is Lupus news sheet.

Grampian Lupus Group Christmas Lunch, Sunday 29th November at 12.30pm

Name: _____ Tel. Number: _____

How many attending?: _____ Cash/Cheque enclosed: _____ (made payable to
Grampian Lupus Group)

**Please return to: Mrs Angela O'Sullivan, 114 Western Road, Hilton,
Aberdeen, AB24 4LX *no later than Thursday 26th November 2009.***