

Lupus Latest

from the
Grampian Lupus Group

CHAIRMAN'S MUSINGS

Hello everybody and welcome to you all.

Firstly may I say how proud and honoured I am to become your Chairman, following in the footsteps of Hugh Morrell and previous to that, Elizabeth Chown, gives me a hard act to follow but I will try to do my best.

I attended my first Lupus UK AGM and Conference this year held in Glasgow and met up with people from all over the UK, most with Lupus and some without,. I also met the new Chairperson for Lupus during the Get Together and we congratulated each other on our appointments.

A very good Conference and AGM ensued and afterwards we all proceeded on our separate ways vowing to attend the next one and judging from the numbers attending and from what they said, they do appear each year.

We have now had the first of our Lunches for the year. No Doctors were invited to this Lunch as it was a special one for Hugh to say goodbye to him.

A good time was had by all who attended, though from looking at the Membership lists a few seemed to have missed out on a very good day, perhaps I will see you at the next one.

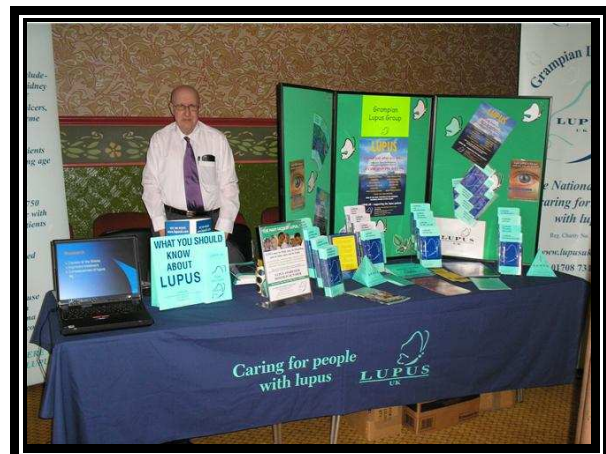
We made our appearance in public this Year on the 25th of July at the

Aberdeen Tenants Open Day where we set up an information Stall, my thanks to all who attended to look after the Stall.

I'm sure that you are looking forward to the Lupus Buffet Lunch in the Northern Hotel on Sunday 5th Oct where I hope to meet even more of you.

That is all from me for now, so how about me hearing from you for the magazine? Jokes, Crosswords, Recipes, Cartoons that we can use to brighten up the Magazine. I call it the Magazine because I this is what I want it to become, a Magazine for you by you for all in Grampian.

Bye for now, see you all soon.



Jim pictured with the Lupus stand at the Tenants Open Day

My INTERVIEW WITH

Jim Fletcher, Chairman

1) What type of Lupus do you have?

I have (S.L.E.) Systemic Lupus Erythematosus and from the Male side of things it does what it says on the tin. Complications are Osteoporosis, (crumbling of the bones) so I am gradually shrinking, Heart problems, Lung problems, and I am not the worst case, others are far worse than me.

2) How does Lupus affect your daily life?

I no longer work (one day I was happily working, the next day was the end of my working life, though I did not know it at the time) I can still do some work for a few hours spread over a week. I have to rest between times so take some time to get things done. I cannot do the things that I used to do so try to find things that I can do.

3) What's your advice to Lupus sufferers?

Chin up, Press on regardless, if you can't do something one way find another way. Don't let yourself be mollycoddled (well sometimes for a treat). Try to look on the Lupus as an inconvenience, something to get round not as an insurmountable object.

4) What do you think are the most important things that the family of a Lupus sufferer can do?

Give as much support as possible without being overbearing. Try to understand Lupus,

(Get in contact with a Committee Member who has practical experience of Lupus, Join us to get up to date info.

5) What is your connection to the Lupus group?

The Late Alf Wilson got in contact with us and invited us to a lunch. We accepted and the rest is history.

6) What are your plans for the Grampian Lupus Group now you have been appointed Chairman?

Change my name to BLYGH and bring back the Cat and the Stocks (and if I ever hinted at that I would not even have a Group let alone a Committee).

NO..... what I will do is talk with the Committee about ways to raise money so that we can continue what we are doing for you the members and how we can assist in the eradication of Lupus, then we shall see what else we can do next.

7) I know that you are connected to other voluntary groups, which are they and in what capacity is your involvement with them?

I have actually given up my work with most of the groups that I worked with since taking up the position of Chairman, I did however work with Hospital Radio as a Presenter for some years, going to College to take an H.N.C. in Radio Broadcasting, very enjoyable, I was Grandad to the rest of the students especially when studying Law. At the moment I am working in Tenants Participation as a volunteer assisting with my colleagues in the setting up of a new style of Participation which I hope will become the benchmark for Scotland.

8) What does a typical day in Jim's life look like?

With a meeting on I get up about 7am to do the usual plus take a couple of tablets then breakfast of cereal and coffee then take a host of tablets on top of that, jump up and down to sort that lot out (joking), then off to the meeting. Home in the afternoon, rest up for a while then turn back into a human being again. No meeting, enjoy the luxury of getting up later, same process for Breakfast then attend to whatever I have to see to, take the odd rest in between and then try out my new Flight Sim, on the computer. And then Good Night.

9) If you were Prime Minister for a week what changes would you make?

I would have a law passed so that all persons with a debilitating condition (not just Lupus) would have access to the medicinal assistance required regardless of cost, providing that it had been proved safe to use.

**Tuesday 30th September
10.30 – 10.40**



Damien McLeod Interviews...

Jim Fletcher

&

Angela O'Sullivan

for

Lupus Awareness Month.

Put your radios on and listen!!

ECLIPSE NEWS - THE LIGHT SENSITIVITY SUPPORT GROUP

LIGHTING UPDATE FROM DAVID PRICE, CO-ORDINATOR OF SPECTRUM

Like everything else things move slowly. The government has made a concession that 25 watt and 40 watt candle and golf ball styles will continue after the ban until a solution is found but only for people who suffer light sensitivity. They would like the various charities to distribute the bulbs but this is not practicable because they do not have the resources.

A letter and various scientific papers have been sent recently to DEFRA, Department of Health, Lighting Association and some MPs. The letter stated that the people who suffer with the proposed lighting systems are the only ones who know what wattage is required in their home. This letter has been approved by all the various charities that SPECTRUM represents and others and the charities' names added to the signature list.

We also have to turn our campaign towards public buildings and street lighting.

The way forward on public buildings is to have the Building Regulations changed but this will not be easy.

On the street lighting it is proposed that the amber sodium tubes be changed for white fluorescent tubes. A letter is being drafted to be sent to the Department of Transport, Department of Health, DEFRA and the Lighting Industry stating that the sodium tubes are energy efficient. It will also state that if this goes ahead sufferers will be made prisoners in their own home and that night time at

present is the only time some can get fresh air and exercise by walking.

I recently obtained some new halogen bulbs from Philips and Osram which are not yet on the market. I have had them tested. There is no UV and the visible spectrum is similar to ordinary incandescent bulbs, but that does not mean they are safe. These are now available for testing by sufferers. If you would like to try one please let me know. I must warn anybody that tries them does so at their own risk.

As I have stated before SPECTRUM is not funded. If you would like to help with the cost please make donations Lupus UK who are looking after any donations, making sure that you mention the donation is for SPECTRUM.

LUPUS EVENTS

Lupus Lunch –

Sunday 5th October, 2008

With Summer seemingly a long forgotten memory we have now booked and our Lunch at the **Aberdeen Northern Hotel at 12.00.**

The lunch will consist of Soup sandwiches, fresh fruit salad and ice cream, with tea or coffee. The cost will be £7.00 per member. We need a minimum of 15 people otherwise we won't be able to secure these low prices again with the hotel., so please do your best to come along and support the group, meet new members and catch up with old friends.

Please contact Angela O'Sullivan before 29th September to secure your place.



WITH ONLY 105 (AT TIME OF WRITING!) DAYS BEFORE CHRISTMAS WE THOUGHT WE'D GET IN EARLY WITH OUR PLANNING SO.....



Christmas Lunch – Sunday 30th November, 2008

NB: THIS IS A REVISED DATE

Booked for 12 noon and will consist of:

Welcome Drink
Soup and Carvery
OR
Carvery and Sweet
with wine and drinks
followed by
tea or coffee.

Cost to members will be **£10.00** per head.

To boost funds a little more we will again have a raffle and have been donated a meal for 2 by the Northern Hotel, along with many other good prizes!



*Bon Accord Centre –
Saturday 18th October
9-00 – 15.00*

To highlight Lupus Awareness Month we have organised a stand at the Bon Accord Centre, which we desperately need volunteers for. We don't want anyone for the whole time (unless you can!!) but just to give up an hour or two on the day to man the stand.



SUGGESTIONS

Hellois there any one out there??Still waiting!!!!

Please contact your Newsletter Editor, Lesley Jenkins on cydrdog@hotmail.co.uk

Your help is needed again

.....We'd really like two volunteers every hour and also a volunteer who will manage to uplift our display equipment and set everything up..... *Please !!*

PLEASE CONTACT JIM FLETCHER ON (01224) 210622 IF YOU CAN HELP WITH THE STAND AND CONTACT ANGELA O'SULLIVAN ON (01224) 495990 IF YOU CAN UPLIFT THE DISPLAY AND SET IT UP AT THE BON ACCORD CENTRE BY SATURDAY 11TH OCTOBER 2008.