



Newsletter - November 2004

Hello from our Founder

Hi to you all – firstly I must apologise for the delay in posting this newsletter on to you. We thought we would give Vanessa a break from this chore and we asked another lady, alas this has not worked out so I am hurriedly putting this together. My apologies to you all

We have had a really good year up to now relating to posting on the ‘early warning signs and symptoms’ and have now covered 1,500 GP’s surgeries. Our aim is to forward 100 each week this will be a 2-year project to cover the 10,000 surgeries. Consultant Microbiologists and Infection Control Nurses are also being covered as and when we can. Stan one of our survivors husband suggested that we attach a ‘feed back form’ to the stationary we will run this for a while – if they do not return them I will stop this to reduce the cost of ink and paper.

The August meeting and the October meeting went well and I feel assured that all who attended got something out of meeting other survivors and bereaved. There will be a North & South meeting again in 2005 so watch out for the dates.

Christmas will be just around the corner and this year it seems to have arrived even earlier. I am sure this is because we have had such a horrendous summer with all the rain. Attached is our selection of Christmas cards for this year so please do support us if you can. They are reasonably priced.

We also have pain stakingly made some Christmas tags so please do order at the same time they are 40p for 12 tags.

I would like to wish you all a happy Christmas and I know for a lot of you it is a time of sadness – rest assured I will be just a phone call away over the Christmas period – please ring me if you want to Tel 01254 878701.

Funeral Donations I would like to thank all concerned for the monies raised from the family and friends of Ian McDonald who passed away earlier this year. A great deal of money has been forwarded and Julia, Ian’s wife and I are having talks on a project that these funds £6,937 could be used for.

Also Carol & John have forwarded monies to us as a result of losing there son Ross. Carol has been Lady Captain of Huntswood Golf Club and has raised £11,000 over the year for our Charity. We have decided to make a training video for all Medical staff to learn more of NF and especially the early warning signs and symptoms. We are to commence early next year with this project.

A big thank you to you all for other amounts raised every penny is really gratefully received.

Amazon Please remember if you use Amazon to purchase any items, first go through any Amazon link on our website. We receive 5% of sales – better than nothing – it will buy a few more stamps!!!

Community of Patient & Public Health I am still attending the monthly meetings and quite enjoying them. A lot of medical issues are open for discussion and all who are members of the forum can add our experiences of any issue raised. Obviously infection control issues are my concern.

While I was away on holiday there was a day training on 'super bug watch' this involves going into Hospitals and random testing the wards at one hours notice. I will have to wait for the next training day so I can go into Hospitals for inspection. The MRSA support group actually lobbied parliament on the 20th October 04 – so watch the press and the TV for a follow up.

Take care & God Bless.

Doreen Marsden

Founder & Chairlady.

How to attract and keep a celebrity I am attending a one day course in Manchester on the 24th November 04. I hope that it will be a useful day in order to find a celebrity to raise awareness for the foundation. I do think that this is a step forward in raising awareness. It should be interesting and I will inform you in the next newsletter how the day went.

Documentary The production company Telescope and myself are starting to film in March 2005. Some survivors have agreed to be filmed and we are very grateful for your commitment in making this documentary so please do wait for a phone call in the New Year from Branyn. I will keep you informed in the New Year of how things are developing.

Richard & Judy I have also been asked to go on the Richard & Judy show as a result of a lady losing her husband to NF. At this moment I do not know what date this will be - again I will inform you via the newsletter. So as you can see lots going on as usual.