



June 07 NF News

Hope you all enjoyed the early hot weather? Shame it did not last very long !!

Lots of information for you as usual in this newsletter. For the new survivors and bereaved I really do hope that your journey of recovery is slowly but surely, if anyone needs to speak with me or another survivor or bereaved I will arrange that for you. Tel/Fax: 01254 878701 or e-mail info@nfsuk.org.uk

Don't forget to keep up with new news on our website www.nfsuk.org.uk we have many polls on the site now and we would really appreciate if you know someone with internet access if they could help you out by completing some of the questionnaires. They are so important and we need desperately for you all to complete the answers for us to get through the red tape. By collecting our own data we will prove to them that there is a problem out there and that NF is not rare.

PLEASE PLEASE help me so I can help you.

NCHI

(National Concern for Healthcare Infections)

We have had talks recently 22nd May with members of the above organisation. They are fighting hard like us to raise the profile of most HAI (Hospital Acquired Infections) We reckon we can shout louder if we all come under the same umbrella as such. So along with some other organisations and charity's we are going to campaign together. I am/we are sure it is the only way forward. Please see the separate sheet for more info on the NCHI. (click here for the net version)

FUTURE EVENTS

Another Clay Pigeon Shoot on our farm Sat 4th Aug 07 it really is a great day out so please do contact me for more info. Last year was a success and we raised £350. Quad bike racing as well as shooting, a walk round the farm. looking at the Aberdeen Angus Beasts and our lovely cuddly sheep the Yorkshire Downs. The calves and the lambs are being born now so you can see those also. Anyway let me know if you are over this way in August. Also we are thinking of organising a Walk 2008 somewhere in the UK to raise awareness. Please do phone me if you and your children would care to take part. Most probably the children would start their walk first and then adults. This event will take a lot of organising i.e.; local councils, insurance etc; so we will keep you informed. Just please do contact us if you would like your names adding to the list. The area we get the most applicants from, then that is where it will be held. If you have any experience in organising an event like this or if any of you have any ideas on other campaigning events please drop me a line or an e-mail. Details are at the bottom of this newsletter.

MEDIA/Campaigning

Debbie one of our survivors has been in a few mags to help us raise awareness – I know how difficult it is to go into these papers and I realise that it must bring so so many memories back for you, so I REALLY do appreciate it.

The production company in Birmingham could not take the idea of a programme on NF any further. The powers that be just do not want to show that type of programme at the moment. So we will patiently wait again. Many journalists get in touch with us asking for a story, but to many have failed to deliver. I am fully aware of your emotions relaying your story again and I fully respect you all.

If I do not feel that we are going to be treated with respect and that dealing with that journalist is going to be fruitful then I shall not/do not go ahead.

I still have not received the CD from the interview re; Radio Europe from 11th Oct 2006 broadcasted from Spain, at least everyone over there heard about NF. I am sure the lady that interviewed me has a son that has been affected by NF – the hospital recognised it straight away. I have a feeling this CD is not going to be delivered now they always say they are having technical problems. So I have give up on that.

Medical Updates

Patsy (Trustee) & I attended an Infection Control Nurses Association (ICNA for short) study day in Harrogate on the 13th June. One of the speakers their a DR M Asios gave a talk on NF – I introduced myself/the charity prior to the conference (pity she didn't know of us in the first place) she was elated to know of the work we are doing and fully supports our campaign. We took 65 DVD's to the conference and we made sure that all the critical care staff in the room received one. We can not hand the DVD's out without charging as we have received the £13,000 grant from the Association of Clinical Pathologists for the distribution of the DVD, Dr M Asios talk was very good and she asked everyone in the room to raise their hands if they had come across the word necrotising ... a few lifted their hands up, I could not believe it. Then she asked if anyone new what Fasciitis meant – no-one raised their hand. I COULD NOT BELIEVE IT. These were critical staff, surely they have learned what the words mean. Perhaps they have not come across a patient with NF but it really did shock me that they did not understand either word.

If you know of anyone including your own GP's that would like a DVD please get in touch – don't forget that they are extremely graphic so please do really think about purchasing one for yourselves.

Surveillance Forms

The HPAgency is still revising this. If you remember I thought it would be a good idea if statistics were collected on the cost to the NHS if a patient was not diagnosed at an early stage. Hopefully we can find another way to make the RT Hon Patricia Hewitt aware of the importance of this infection. So the form is in their hands until further notice. When I receive this back I shall inform you.

Department of Health Biomedical Research Centres update from Prof Peter Winstanley MD FRCP.

“Preparations to establish the Biomedical Research Centre on Microbial Diseases at Liverpool are moving forwards. The hospital is in discussion with the Department of Health concerning the details of the budget, and is currently in the process of setting up its committee structure. Planning the necessary refurbishment of clinical and laboratory space is well advanced.”

Peter Winstanley MD FRCP
Meeting arranged for 23rd August in Liverpool.

Funds

If you remember Catherine Cox and her family had a memorial get together in S Wales on the 3rd March in memory of their mum who passed away from NF. The evening was a success and they raised £1,200 fantastic thank you to you all for all your hard work. And a BIG thank you to all those people that have forwarded money to our charity and also completed the Gift Aid form the money has now been received from the HM Revenue & Customs £720.46p and has been deposited direct into our bank account – I think it is fantastic thank you. Karen has done a sponsored slim and raised £237.35 for us and lost 23lb –marvellous heh?

I could go on and on with what we have achieved. I know you all know that we are working so very hard for you all. The newsletter would be extremely long winded so I will stop now. If you do want to know anymore please do phone me or look on the site. www.nfsuk.org.uk

Well that's all for now goodbye love & respect to you all.

Doreen & all the trustee's Xxxx

'Pursue inner peace. It's the deepest of all blessings'

P.s If any of you have an e-mail address could you please e-mail me so I can remove you from our postal newsletter delivery. Save a stamp heh!!