



Fibrous Dysplasia Support Society

FIBROUS DYSPLASIA SUPPORT SOCIETY NEWSLETTER – MARCH 2009

Hello Everybody!

Yes it's been a while so Merry Christmas, Happy New Year and almost Happy Easter all in one go.

There's been plenty happening for our Group over the past few months, here's a whistle-stop tour of the bits that I can remember:

At the AGM in October we welcomed Elizabeth Littlewood and Jamie Watson to the FDSSUK Committee, and they bring valuable experience to the team from which we will all benefit. Also we were pleased that Franzesca Watson was able to stay on the Committee for a while longer. It was a shame that we had to cancel the October 08 meeting in Birmingham but the response really did not warrant the expense of renting the room. Hopefully we will be better able to support such an event this year and we are actively pursuing medical speakers at the moment. If you have any suggestions of someone with FD expertise who would like to come and give us the benefit of their wisdom then let please us know.

We have had some immensely generous gifts over the last few months from people within the group and their families. I'm not going to embarrass anyone here, but you know who you are and, hopefully, how grateful the Society is for your generosity and support. For example, people supported us in the Great North Run, and Walk; the daughter of one of our members raised money at her school. Terrific, thank you.

We have already started to put this money to good use! Ann Underhill has been working hard with a web developer to get our website up and running, and Franzesca Watson has validated the details we hold of FD medical professionals in the UK. Thanks both! We think the website is not too far away now. We're going for a relatively simple site that holds useful information for anyone with an involvement in FD/MAS, either through their own experience, as a supporter, or the medical profession. It will also act as a resource for our established members to keep in touch with what the group is doing and latest FD information.

So those are the big things that come to mind, no doubt I've missed plenty of other stuff too. That's what comes with age! With summer approaching, I hope that we all make the most of it. FD slows us all down to a greater or lesser extent, but (in my humble opinion!) it also makes us pretty determined people who get the most we can from life. So here's hoping that the weather gods smile upon us this year, after last year's gloom. It was not the best year to tackle a motorcycling project that took me 7500 miles to far flung parts



Fibrous Dysplasia Support Society

of the UK through the so called summer months; the West Coast of Scotland was memorable - I never knew it could rain that hard for that long! Oh well, you can't have everything.

Take care
Kevin
Chair FDSSUK