



Fibrous Dysplasia Support Society

FIBROUS DYSPLASIA SUPPORT SOCIETY NEWSLETTER – FEBRUARY 2010

Hello All,

May I be the last to wish you all a Happy New Year! I hope this finds you all fit, well and looking forward to Spring. I've had enough of winter and am sure that you have too. Down in the balmy South we have had a lot of snow for this part of the world, but nowhere near as bad as you hardy souls up north (i.e. far side of Newbury). It was one of the few times when I've felt all too aware of the FD presence in my undercarriage; for a few days I walked the couple of miles to work and shuffled along like an old Granny so as not to end up on my backside. I hope you all came through it intact too.

A quick update on events of the past few months: As you will know by now we have our website up and running (www.fdssuk.org.uk). It has already proved useful several times as a reference point when we have had enquiries from various directions. I hope you like it, but let us know if you have any suggestions to add.

We continue to have some really generous donations and to each of you who have helped the cause we are extremely grateful. We won't embarrass anyone here, but we know who you are and appreciate it very much indeed. At risk of sounding boring, we do rely on donations as the sole source of our funding and people continue to come up with imaginative ways to raise money.

In October we had our annual meeting in Birmingham. It was great to see such a good turnout, especially the number of new faces who came from far and wide for the day. For me the key benefit is always to meet other people and learn more about the condition. This time we were lucky enough to have Dr Michael Davie who is Consultant Physician / Clinical Director of the Charles Salt Research Centre for Human Metabolism in Oswestry come and speak to us. It was great to listen to someone with so much knowledge of FD/MAS tell us about its origins and treatments. We also had a lively Q&A session where Dr Davie took every question that was asked and answered it in a really clear and helpful way. He was generous enough to stay with us far longer than we expected to make sure everyone had a chance to contribute. We also attended to the business of the day with our AGM. We are always careful to cover all the required aspects, but try to keep it as concise as we can; this allows more time for everyone to chat and learn. There were a few committee changes: Sue Szablewski will be taking a well earned rest from the Secretary role (thanks for all your hard work Sue). She is not going anywhere though, and has agreed to stay on the committee looking after the medical liaison aspects. Ann Underhill has moved across into the Secretary role. Neil Buck, who has been involved in the Society since the start, has also joined the committee. Otherwise the committee is the same as last year. The full minutes will be appearing on the website soon.



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Looking ahead, we are now thinking about speakers for this year's meeting, so if you know someone suitable, we would be pleased to hear from you!

One other little project we are about to start is getting a map together (maybe on Google Maps or similar) of where our members live so that we can put people in contact with someone near if that will help. More on that in a later email.

So, that's about all that has come into my aging brain for this edition, no doubt there's plenty I've forgotten. We've got Spring and Summer ahead to enjoy - we have to get a good one soon don't we? So get prepared (the motorbike now has new tyres so I'm ready!), get planning, and make sure you enjoy it!

Take care
Kevin
Chair FDSSUK