



Registered Charity No. 1135020

Fanconi Anaemia Family Support Spring Newsletter

<http://www.fanconisupport.info>

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A bi-annual (6-monthly) Publication of "Fanconi Anaemia Family Support"

22nd March 2009

Welcome to the 1st Newsletter of Fanconi Anaemia Family Support –

BY Families WITH Families FOR Families

The 1st Fanconi Family Support Meeting

On Saturday 20th March 2010, at the Holiday Inn in York, we held our first Family Support Meeting. A total of 14 Families attended – the make up of these Families was - 22 "parents", 4 young adults, 9 teens and 19 children under the age of 11. Of the people actually at the meeting, there were a total of 9 people with FA (aged 1, 2, 4, 8, 13, 13, 16, 20 and 25).

It was a lovely opportunity for Families to meet each other and chat, discussing a range of issues relating to FA and providing mutual support.



Even though there had been an opportunity in the morning for Families to introduce themselves and talk freely, it was lovely to see Families and professionals mingling and chatting over lunch.

Professor Sally Kinsey (from Leeds Teaching Hospitals) gave a very informative talk about general FA management issues and treatment options and Evelyn Ward, Dietician (also from Leeds Teaching Hospitals) gave very useful advice about FA dietary issues. Ralf Dietrich, from the German FA Support Group was there to offer advice and support, and he was able to further very important research, gaining oral samples and photographs from 5 FA patients.

The children had a wonderful time in the nursery and our heartfelt thanks go to Sonia and Diane for giving up their time to look after and play with the children in our separate "crèche" facility. There was a good selection of toys kindly loaned by the City of York Council "Toy Bus" and both rooms (the main meeting room and the children's room) were exactly what we wanted – our warmest thanks to the Holiday Inn for their help and support. The muffins seemed to be a great success, thank you so much everyone – between muffin sales and some generous donations, we managed to raise £200; well done everyone, that is a good start in getting funds together for our next meeting.



Could this possibly be the first meeting of our "Teen Group"? Four of our teens manage to escape the main meeting room and the adults to have a chill. When we organise the next meeting, we hope to have a Teen / Young Adult room.



This is one photo of the "crèche"; it was the hardest photo of the day to take. The little ones were so fast, most of the photos taken were a blur. This was a success and we will have the same facility at the next meeting.

The Future

Where do we go from here? The simple answer – we grow. Another meeting, maybe for a weekend – more time, more FAMILIES involved, more activities, whatever FAMILIES want. In order for this to happen, we need to ask for help in fundraising. This is **OUR** group, we all have a say in what the future holds and we can all help to make things happen.

Keep an eye on the website for updates – <http://www.fanconisupport.info>

Fundraising

So far, we have organised a cake sale (raising £200); Ashleigh McDowell and a group of friends are going into Malton in pyjamas, with pink buckets to do a moving street collection; we have placed collecting tins in some local businesses and we have had requests for several more. A few of the FAMILIES at the meeting have already discussed some good ideas and offered to help – thank you so much. We are also planning to organise a few local events. If anybody has any other ideas or plans for fundraising, please let us know; we can help to get it organised and provide collecting tins, information, logos, etc.

Point everybody you know to our website; they can make online donations or send cheques.

If anybody you know ever shops online, ask them to help us by going via this website –

<http://www.buy.at/FAsupport>

It won't cost you any extra, there are around 150 online retailers (shops), you shop in the normal way (just go to their website from the address above) and we receive commission.

International FA Day – 1st May 2010

The inaugural International Fanconi Anaemia Day is set for 1st May 2010. This kicks off a week long event worldwide to raise awareness and funding for research. We are trying to organise local media to run stories about FA and we are planning some fundraising events in our local area to both raise awareness and fundraise for "Fanconi Anaemia FAMILy Support". Please join us and support this wonderful initiative – if you could involve local media in your area and organise events that would be Fantastic but you could also help by sponsoring our events or making cash donations. For further information, please visit our website.