



Registered Charity No. 1135020

Fanconi Anaemia FAMILY Support Spring Newsletter

<http://www.fanconisupport.info>

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An annual Publication of "Fanconi Anaemia FAmily Support"

16th March 2011

Welcome to the 2nd Newsletter of Fanconi Anaemia FAmily Support –

BY FAmilies WITH FAmilies FOR FAmilies

The 2nd Fanconi Family Support Meeting

Following the success of the first meeting on Saturday 20th March 2010, at the Holiday Inn in York, we decided to organise a full weekend this year. We booked out almost all of the holiday cottages at Claxton Grange and provided meals and refreshments for the whole weekend – there was no cost to the FAmilies attending, although donations were made (and gratefully received, of course). A number of last minute cancellations due to illness and work commitments reduced the number of FAmilies to 10 but this made for an intimate weekend, which proved very rewarding for all. Thanks to "2chefs.co.uk" for a lovely buffet lunch on Saturday and the "Jinnah Restaurant" at Flaxton for a wonderful meal and evening – a kind donation by owner Saleem Akhtar covered almost a quarter of the cost of the meal. Saleem has also suggested that he organise a fundraising event for us in the summer!

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. Some FAmilies arrived on Friday for a relaxing evening and the remainder arrived on Saturday for the main meeting.



Saturday began with a continental-style buffet breakfast in the Garden Room, followed by an informal session, allowing FAmilies to introduce themselves and get to know each other. This led to some slightly more formal "presentations" by the professionals present – Professor Sally Kinsey (Paediatric Haematologist from the Leeds Teaching Hospitals) gave a very informative talk about FA101, general management issues and treatment options; Evelyn Ward (Paediatric Dietician from the Leeds Teaching Hospitals) provided useful information and advice about dietary issues; Colleen Lynch (Embryologist from CARE in Nottingham) was on hand to offer advice about PGD-IVF (Pre-implantation Genetic Diagnosis).

Ralf Dietrich (FA parent and President of the German FA Support Group) and Dr. Eunike Velleuer (Paediatrician from the Clinic for Haematology and Oncology at the University of Dusseldorf) discussed Squamous cell Carcinoma / oral issues and were able to further their very important research, gaining oral samples and photographs from 5 FA patients, using their brand new STORZ oral endoscopic photodocumentation equipment. Although, the work that Ralf and Eunike do is "research" and not diagnostic, with the experience they have gained (almost 400 FA patients worldwide), there is absolutely no doubt that a great number of people have benefitted from being seen by this "dynamic duo": Lives have been saved.



Inside Ralf and Eunike's "Waiting Room"



Eunike starts an oral "examination"

Here is an important bulletin from the FARF website:

"As you'll read in our upcoming FA Family Newsletter (to be mailed at the end of March), Dr. Eunike Velleuer reports that of the 370 FA patients she and Ralf Dietrich have interviewed, 85% admitted that they were not screened regularly for oral lesions that may be a sign of head and neck cancer.

Why? Human nature, i.e., reluctance, procrastination, or lack of information, might account for much of this non-compliance.

In an effort to continue to educate FA patients and their families about the significant increased risks of head and neck cancer in FA, this email is a reminder of the need for aggressive surveillance. As taken directly out of our handbook, Fanconi Anemia: Guidelines for Diagnosis and Management (page 255): 'Surveillance should begin by the ages of 10 – 12 years ...on a semiannual basis by an experienced professional; i.e., an ear, nose and throat specialist, an oral surgeon or other doctor experienced in head and neck cancer detection and treatment. Since head and neck cancer in patients with FA commonly occurs in the oral cavity, the surveillance approach should focus on this region. However, as part of the routine screening, a flexible fiberoptic examination should be performed which includes evaluation of the nasopharynx, oropharynx, hypopharynx, and larynx. The use of routine esophagoscopy for screening is not mandated but should be considered in any patient with odynophagia, dysphasia or other localizing symptoms...'

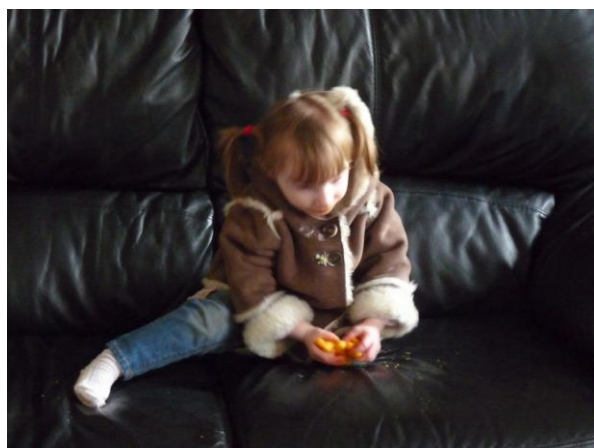
While the minimum recommendation for head and neck cancer screening is twice per year, if you notice any questionable areas ever, you should have them examined immediately and not limit the screening to twice per year.

Just as important is a reminder that drinking alcohol and using tobacco products can significantly increase the risk of oral cancers. We encourage FA patients to consider the consequences before drinking and smoking."

Whilst the adults were in the meeting room, the children had a wonderful time in the “crash cottage” and our heartfelt thanks go to the staff from Ryedale Special Families for giving up their time to look after and play with the children in this separate “crèche” facility. We had numerous comments about how wonderful Charlotte and Ian (and Ash, of course) were. There were a good selection of crafts and toys, including a PS2 for the older ones.



There were definitely more kids than this; some were in the kitchen and I’m sure some must have sneaked off upstairs!!!!



What a mucky face!!!

“I’m sure I can get more Wotsits in my hands!!”



A lovely meal and a fun time was had by all at the Jinnah Restaurant, Flaxton, York. The staff were very friendly and nothing was too much trouble for Saleem and the team.

Thank You For Your Generosity

£300 from Kim Ayling on behalf of the "Daniel Ayling Fanconi Anaemia Trust";
£179.45 from FAmilies present at the weekend (this included sale of a few T-shirts);
£100 from Saleem Akhtar at the Jinnah Restaurant, Flaxton, York;
£472 from Liz Welburn (a sponsored flight in a small aircraft doing aerobatics / stunts).

The Future

Where do we go from here? We grow. Another meeting next year, again for a full weekend, maybe a long weekend from Friday to Monday, with more professionals present – more time, more FAmilies involved, more activities. Whatever FAmilies want, we will respond to. 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.

Fundraising

Our current initiative is "**2 pound 2 pound FA**" (£2 to pound FA) – please make a donation and encourage as many people that you know as possible to do the same. We don't expect anybody to make huge donations because we know these are difficult times. Rather than a few people donating lots of money, we want to try to encourage lots of people to donate a little money. The idea behind this campaign is that people give as much or as little as they can afford – a one off donation of £2 or £2 per month or maybe even £2 per week – every little bit helps. Just think if 100 people each give £2 per month – that's £2400 each year BUT imagine if that was 1000 people or maybe more!!!!

Direct people to our website where they can find our address to send a cheque, a standing order form that can be downloaded or a link to our Charity Giving site:

<http://www.charitygiving.co.uk/fundraising/fanconisupport/>

If anybody has any ideas or plans for fundraising, please let us know; we can help to get it organised and provide collecting tins, information, logos, etc.

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 2011

Following on from the success of the first International Fanconi Anaemia Day, this is set to continue for the future. 1st May 2011 kicks off a week-long event worldwide to raise awareness and funding for both FAmily Support and 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 to support this wonderful initiative – you could involve your local media and organise events but you could also help by sponsoring others or making cash donations.

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