



Fibrous Dysplasia Support Society

Minutes of the 2012 Annual General Meeting

Held at 10am on 13 October 2012 at the Royal National Orthopaedic Hospital (RNOH), Brockley Hill, Stanmore, Middlesex, HA7 4LP

<p>1.</p>	<p><u>Present</u> Kevin Bittlestone/Sarah Russell (Chair) Jamie Watson (Treasurer) Lisa Scoates (Secretary)</p> <p>Cecil Lawrence, Ian Crisp, Kate Mee, Sue & Frank Szablewski, Sheila & Ray Cook, Jamie Feeney, Mark Pickford, Trish Jones, Millie Pickford, Elaine Walker, Heidi Sidebottom, Jon Price, Mandy Fender, Peter McBride, Bethan Davies, Edwin Aslin, Diane Law, Julie Humphreys</p> <p><u>Apologies</u> Ann Underhill, Jennie Bouron, Elizabeth Littlewood, Rebecca Murchie, Gary & Jane Liversidge, Caroline Robson, Tracey Lister, Aruna Jago-Brown, Angela Davis, Christine Deane, Helen & Pete Clements, Stephen Mc Murray, Heather Delaney, Stephen McMurray, Joanne Wain, Chloe Game</p>	
<p>2.</p>	<p><u>Welcome and Introductions</u> – Kevin opened the meeting and introduced himself and other committee members.</p> <p>Kevin gave a brief background on the group, how it was formed and by whom, for the benefit of the many new members at the meeting.</p> <p>Members were then invited to share their own experiences of FD/MAS with the group and their reasons for joining the group/committee; however this was continued later on in the meeting as Professor Briggs arrived.</p>	
<p>3.</p>	<p><u>Professor Briggs, Consultant Orthopaedic Surgeon & Director of Strategy & External Affairs, RNOH</u> – Professor Briggs began by giving a background to the RNOH and explained that it has developed an excellent reputation as one of the leading orthopaedic hospitals in the UK. The hospital looks after on average 100,000 outpatients per year and carries out approximately 12,000 operations. It has a 0.2% infection rate and has recorded zero cases of MRSA during the last 3 years. The hospital treats both common and very complex orthopaedic work.</p> <p>A great deal of work goes into future research and development and the Professor spoke briefly about a high-tech new technology called ITAP.</p> <p>The hospital sees 3,500 tumours per year and the Professor is a member of the London Sarcoma Service.</p> <p>He then went onto talk more specifically about Fibrous Dysplasia (FD) and how he is seeing more and more patients with the condition. It is likely that a lot more people have some FD but will not know it as it remains undiagnosed. There are some medical professionals who</p>	

believe there is some question around whether it is genetic, however as yet there is no real evidence to prove this theory.

The Professor explained that FD is most commonly first seen in patients between the ages of 3-15 years. Children that experience night pain should be taken seriously and their symptoms investigated as this is common in children with FD.

It is caused by a gene mutation that affects the cells that produce bone. This results in the bones breaking down quicker in FD patients which in turn causes scar tissue. Affected bones in FD patients have the appearance of ground glass. The condition is described as monostotic if it appears in only one bone and polystotic where FD appears in multiple bones. Over 50% of those with FD will have it in their face/skull.

As well as other symptoms FD usually causes pain that is local to the affected bones and swelling. Additional complications/side effects can be cafe-au-lait spots; hyperthyroidism and precocious puberty. There is also a risk of fracture in the hips and of patients having Mazabrauds Syndrome.

Investigations to diagnose FD include x-rays; MRI and bone scans. The Professor explained that often after diagnosis patients will just be observed regularly as a lot of the time for some patients FD will not cause any problems. For those that require treatment/pain management bisphosphonates can be administered. Bones can be pinned to strengthen them and occasionally the lesions may be removed from the affected bones.

Professor Briggs completed his talk by explaining that the risk of developing malignant tumours as a result of FD was very low and less than 1%.

He then invited questions from members which included:-

Q. Can Mazabraud's tumours come back after removal?
A. Mazabraud's will not come back

Q. Why would a tumour suddenly show rapid growth after a period of no growth?
A. No real reason for this, just something unknown that triggers it.

Q. What can be done with compression fractures in the spine?
A. Vertoplasty is an option but there are risks to this procedure.

Q. A member's daughter has got polystotic FD in her skull. Should she have a full body scan to check if FD in other areas?
A. No, unless she is having specific pain she should be encouraged to get on with life, there is no need to over-investigate.

Q. The role of vitamin D in the treatment of FD?
A. there is lots of research currently going on around this and bisphosphonates.

Q. I have been told not to get pregnant due to the FD. What would you advise?
A. Absolutely no reason why you shouldn't, in fact some members reported that they had less pain when they were pregnant.

Professor Briggs concluded by sharing his own experience of having a child with a challenging condition. His daughter has Cystic Fibrosis, but despite this he strongly believes that it is important to live life to the full. He urged members with FD/ children with FD to live life to the full.

	<p>A copy of the Professor's powerpoint presentation will be made available on the society website in due course.</p> <p>Member's introductions then continued.</p>	Ann/ Lisa
4.	<p><u>Minutes of the last meeting/matters arising</u> – Matters arising from the minutes were as follows:-</p> <ol style="list-style-type: none"> 1. Ian reported that he has been unable to produce copies of the FD disc. Kevin agreed to send Ian another copy for Ian to use 2. Lisa will send out a link to the FDSS UK Facebook site as some members reported that they could not locate it when searching <p>The minutes from last year's meeting held on Saturday 22 October 2011 were then approved by all present.</p>	Kevin/ Ian Lisa
5.	<p><u>Secretary's Report</u> – Lisa reported that the Facebook page has grown in popularity recently and has attracted many new members to the society. It is now 'liked' by 149 people with lots of different conversations happening between people about their experiences of FD, diagnosis and treatment options. A couple of members have expressed they would like to access the Facebook page but are concerned about the security of sharing their information on it. It was agreed that Lisa would look into this; however increasing security may restrict people from finding it which we would want to avoid.</p> <p>An Easyfundraising account dedicated to raising funds for the society was set up in 2011 and now has 8 members. It works in a similar way to many other loyalty shopping sites, but instead of earning points when you shop, you raise a donation for your cause instead.</p> <p>You can shop with over 2,000 well known stores and each will donate up to 15% of what you spend.</p> <p>It is free to register and does not cost consumers any more than it normally would by going to a retailer's website direct. Flyers were handed out with details of how to register, all of which can be found using the following link, http://www.easyfundraising.org.uk/causes/fdss</p>	Lisa
6.	<p><u>Treasurer's Report</u> – Jamie reported that the bank balance currently stood at £4075.88. Copies of the bank statements were available at the meeting should anyone wish to see them.</p>	
7.	<p><u>Chair's Report</u> – Kevin reported that membership had risen quite significantly during the last year; some of these new members had found the society through the Facebook page.</p> <p>He requested that members remember to keep the society updated with any changes to their email addresses.</p> <p>There has been good feedback from those members who have contacted each other as a result of Kevin emailing out requests from new members.</p> <p>Kevin has been Chair for 5 years and has enjoyed his time in the role. The society has come a long way since its beginning and it has been rewarding to get positive feedback from members whom the group has</p>	

	<p>helped.</p> <p>Kevin completed his report by thanking Lisa and Ian for organising this year's meeting.</p> <p>He then handed over to Sarah who will take over the role officially from today's meeting.</p> <p>Sarah shared that she was first diagnosed with FD when she was 9 years of age. Despite doctors warnings Sarah chose a career in nursing which she finds challenging due to her FD but she really enjoys. Sarah is currently a ward sister at University College Hospital, London. As she has got older she has learnt more about FD and would now like to use her own experiences of FD in her role as Chair of the society.</p>			
8.	<p><u>Election of Executive Committee/Committee</u> – Sue Szablewski was a stand-in Chair for these elections.</p> <table border="0" data-bbox="204 719 1182 1234"> <tr> <td data-bbox="204 719 703 1039"> <p><u>Executive committee</u> Chair: Sarah Russell <u>Proposed by:</u> Kevin Bittlestone <u>Seconded by:</u> Kate Mee Secretary: Lisa Scoates <u>Proposed by:</u> Kevin Bittlestone <u>Seconded by:</u> Ian Crisp Treasurer: Ian Crisp <u>Proposed by:</u> Jamie Watson <u>Seconded by:</u> Frank Szablewski</p> </td> <td data-bbox="703 719 1182 1234"> <p><u>Committee</u> Kevin Bittlestone <u>Proposed by:</u> Sue Szablewski <u>Seconded by:</u> Heidi Sidebottom Ann Underhill <u>Proposed by:</u> Lisa Scoates <u>Seconded by:</u> Ian Crisp Elizabeth Littlewood <u>Proposed by:</u> Jamie Watson <u>Seconded by:</u> Kate Mee Jamie Watson <u>Proposed by:</u> Kevin Bittlestone <u>Seconded by:</u> Sarah Russell Heather Delaney <u>Proposed by:</u> Lisa Scoates <u>Seconded by:</u> Ian Crisp</p> </td> </tr> </table>	<p><u>Executive committee</u> Chair: Sarah Russell <u>Proposed by:</u> Kevin Bittlestone <u>Seconded by:</u> Kate Mee Secretary: Lisa Scoates <u>Proposed by:</u> Kevin Bittlestone <u>Seconded by:</u> Ian Crisp Treasurer: Ian Crisp <u>Proposed by:</u> Jamie Watson <u>Seconded by:</u> Frank Szablewski</p>	<p><u>Committee</u> Kevin Bittlestone <u>Proposed by:</u> Sue Szablewski <u>Seconded by:</u> Heidi Sidebottom Ann Underhill <u>Proposed by:</u> Lisa Scoates <u>Seconded by:</u> Ian Crisp Elizabeth Littlewood <u>Proposed by:</u> Jamie Watson <u>Seconded by:</u> Kate Mee Jamie Watson <u>Proposed by:</u> Kevin Bittlestone <u>Seconded by:</u> Sarah Russell Heather Delaney <u>Proposed by:</u> Lisa Scoates <u>Seconded by:</u> Ian Crisp</p>	
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9.	<p><u>HMRC Constitution update</u> – Kevin shared with members details of some minor changes that need to happen in order for the society to achieve its charitable status. It was agreed by all members that these changes should be approved. Kevin will update and send a copy to HMRC.</p>	Kevin		
10.	<p><u>Support for FD Foundation's project for bound copies of Orphanet Journal of Rare Diseases</u> – It was discussed as to whether members felt it was worth investing in a couple of hard copies of this publication. Although general consensus was that it could be a very useful resource for the society, the question of cost was discussed and the fact that only a section of it would relate to FD. A member enquired as to whether the journal was available online and it was agreed that this would be investigated.</p> <p>Kevin agreed to feedback to Ann as it was added to the agenda at her request.</p>	Kevin		
11.	<p><u>Plans for the coming year</u> – Kevin led this discussion. He began by sharing details of developments since the society's foundation and first meeting in October 2007 at the NEC in Birmingham. It was then that the constitution was agreed. The society has always been funded by donation rather than a subscription scheme, it was generally agreed that it should be continued in this way for the foreseeable future. Since the launch of the society's website in 2008 membership has seen a steady growth. A Facebook page was created in 2010 as a result of</p>			

	<p>discussion at a previous AGM; in 2010/11 the society received quite a lot of media interest and the most recent development in 2012 has been the society gaining charitable status through HMRC.</p> <p>Some members felt that to produce a book/leaflet about FD for those children that have the condition in easy to understand language. This would need to be done with sensitivity so as not to be frightening.</p> <p>Another idea put forward was to produce 'business cards' that could be placed in hospitals/GP surgeries etc as a way of raising awareness about FD.</p> <p>Another member felt it was important to update the list of medical experts currently held on the society's website as this was now very out of date. Alongside this could be a 'refresh' of the website generally.</p> <p>Elaine Walker who is an FD nurse based at Sheffield Children's Hospital attended the meeting for the first time and spoke briefly about the work of the Sheffield National Centre for Children's Bone Disease. Professionals at the centre are keen to become a specialist centre for FD patients.</p> <p>Elaine raised the idea of producing a 'passport' which would hold details of member's individual treatment. She also suggested that the society forms an FD advisory board with medical professional's representation. This could be initiated by contacting all the metabolic bone units across the UK. It was agreed that Lisa would look into this initially.</p> <p>A variation in venue for the AGM was also discussed by members and Elaine put forward Sheffield Children's Hospital as a possible venue for next year's meeting. A venue in Birmingham was also offered by another member. It was agreed that to have Mike Collins, MD from the National Institute of Health, USA to attend next year's meeting would be the ideal and extremely valuable, however, this may not be possible due to commitments and cost. As an alternative it was suggested that we could link up with him via Skype during the meeting as he is considered the world expert on the condition.</p> <p>Elaine then talked of FD treatment options such as Pamidronate and Zolodronic Acid. She explained that there is current research into these and other options too as well as research into the effects that these drugs have on children, particularly babies.</p> <p>She also talked about transition from child units into adult units and the problems this can cause if not handled correctly. Elaine explained that in Sheffield they run transition clinics. She advised that if members are finding problems with transition they should ask the hospital for details of their transition programme as all hospitals should have one.</p> <p>Elaine concluded by saying that members should ask for second opinions if not satisfied and that each young patient should be assigned a specialist nurse.</p>	Lisa
12.	<u>Close</u> – The meeting was closed by Kevin at 1530.	
13.	<u>Date of next meeting</u> – It was suggested that October was a good month to have the meeting avoiding the half term holiday.	