



**MINUTES OF THE 2011 ANNUAL GENERAL MEETING**

**Held at 10.00am on Saturday 22nd October 2011  
Seminar Room 1, RNOH, Brockley Hill, Stanmore,  
Middlesex, HA7 4LP**

1.	<p><b><u>Present</u></b> Kevin Bittlestone (Chair) Ann Underhill (Secretary) Jamie Watson (Treasurer)</p> <p>Richard Mee, Sarah Russell, Ian Crisp, Lisa Scoates, Elizabeth Littlewood, Barbara Kenah, Peter Kenah, Cecil Lawrence, Heidi Backman, Dion Chambers, Peggy Chambers, Sharon Chambers, Lydia Gurr</p> <p><b><u>Apologies</u></b> Eve Marie Webster, Val and Peter Hill, Stephen McMurray, Heather Delaney, Aruna Jago-Brown, Karen Mikkleson, Doris Walker, Angela Davis, Assumpta Begley, Damian Barnett, Helen Clements, Jennifer Williams, Jenni Bouron, Sue &amp; Frank Szablewski, Ray &amp; Sheila Cook</p>	
2.	<p><b><u>Introduction and Chair's Report</u></b> Kevin started the meeting at 10.15am by welcoming all the attendees. As there were several new members we started by introducing ourselves.</p>	
3.	<p><b><u>Minutes of the Last Meeting</u></b> The minutes of the last meeting held on the 16th October 2010 were approved by all present.</p>	
4.	<p><b><u>Secretary's Report</u></b> Ann said that the NIH (National Institute of Health, in America) has started to raise funds for research into FD. The FDSSUK Society now has an entry on the <a href="http://www.orphanet">www.orphanet</a> site. The 'Quality of Life' survey among FD patients/carers has not</p>	

	<p>proceeded due to lack of funding.          Jamie has done all the work to get us a Charity number and we are now waiting for Customs to get back to us.</p>	
5.	<p><b><u>Treasurers Report</u></b>          Jamie gave a verbal report. Our expenditure last year consisted of room hire fees for the 2010 meeting and rental for our web site.          He had been given, at the meeting, two cheques; one of them was for £250 which had been raised by a patient's grand-mother who was sponsored in the Great North Run.</p>	
6.	<p><b><u>Chairs Report.</u></b>          Kevin said that although it had been a quiet year membership had grown to 92.          The society had received four approaches from TV companies, asking for participants in various documentary programs, which he had forwarded to members. He had no idea if anyone had followed up on these requests but he had received a varied response from members with some for him forwarding these communications and some against it. He feels that it is up to the members to decide whether or not to get involved and that, if he receives further requests, he will continue to forward them.          He thanked Sheila Cook for her work in researching suitable Charitable Trust Funds for us to apply to. So far, we have approached seven, with three replies, all rejections.          He further thanked Lisa Scoates for setting up the Facebook page.          He also thanked Ann for arranging the meeting.          He mentioned that we really need a supply of the DVD's created at the FDF (Fibrous Dysplasia Foundation) meeting in 2006. These are a good resource for someone newly diagnosed with FD. Ian said that he will try to copy some sets.</p>	IAN
7.	<p><b><u>Mr R Bhumbra. Senior Registrar on the Bone Tumour Unit at the RNOH, Stanmore.</u></b>          Mr Bhumbra started by giving us a brief history of the RNOH, Stanmore. The philosophy at the RNOH has been, and is, to treat a patient for life. This philosophy is under threat due to the financial pressures on the NHS.          Its role is that of a specialist orthopedic hospital and it is at the forefront in the design and manufacture of orthopaedic implants. Staff from the RNOH have started going out to other hospitals to advise on traumatic injuries and they are also involved in significant amounts of rehabilitation, not necessarily involving surgery, but may involve counselling and the Physical and Occupation Therapy departments.          The RNOH has been under the threat of closure for some years</p>	

	<p>but a new facility is expected to open in 2014. This will have 50 less patient beds,</p> <p>The RNOH has links to the military and recognizes that the military have unique medical and surgical experiences that the NHS must learn from. Historically, the greatest advances in medicine have been made during periods of warfare but, Mr Bhumbra added, in this respect Afghanistan does not compare to a world war.</p> <p>He then went on to talk about FD. FD is a diagnosis which involves a spectrum of disease. FD means different things to different people. The team at the RNOH is probably the most experienced in the UK in treating FD.</p> <p>It is not known how many people have FD which never presents a problem.</p> <p>Typically, weight bearing areas with FD start to bend and stress fractures are generated.</p> <p>Q: What are the chances of FD growing back once it has been removed?</p> <p>A: Low.</p> <p>Associated conditions:- Endocrine - hypothyroidism, phosphatemia, acromegaly, hypoprolactinemia, Cushing's syndrome. Non-Endocrine areas that can be affected – brain, thymus, heart, bone marrow, liver, spleen and GI tract.</p> <p>For endocrine problems he would advise seeing Dr Keene.</p> <p>Conditions associated with FD are MAS, Mazabrauds and a higher rate (approx.4%) of malignant tumours.</p> <p>Any FD patient can ask to be referred to either RNOH (Stanmore) or ROH (Birmingham).</p> <p>Areas of FD should be treated by a bone tumour specialist. The Bone Tumour specialist hospitals in the UK are at RNOH, ROH, Newcastle and Oxford.</p>																			
7.	<p><b><u>Election of Executive Committee and Committee</u></b></p> <p>Ian Crisp acted as stand in chair for these elections.</p> <table border="0"> <tr> <td>Chair: Sarah Russell</td> <td>Proposed: Ann Underhill</td> </tr> <tr> <td></td> <td>Seconded: Kevin Bittlestone</td> </tr> <tr> <td>Secretary: Lisa Scoates</td> <td>Proposed: Ian Crisp</td> </tr> <tr> <td></td> <td>Seconded: Ann Underhill</td> </tr> <tr> <td>Treasurer: Jamie Watson</td> <td>Proposed: Kevin Bittlestone</td> </tr> <tr> <td></td> <td>Seconded: Elizabeth Littlewood</td> </tr> <tr> <td>Committee: Ann Underhill</td> <td>Proposed: Ian Crisp</td> </tr> <tr> <td>Kevin Bittlestone</td> <td>Seconded: Jamie Watson</td> </tr> <tr> <td>Elizabeth Littlewood</td> <td></td> </tr> </table>	Chair: Sarah Russell	Proposed: Ann Underhill		Seconded: Kevin Bittlestone	Secretary: Lisa Scoates	Proposed: Ian Crisp		Seconded: Ann Underhill	Treasurer: Jamie Watson	Proposed: Kevin Bittlestone		Seconded: Elizabeth Littlewood	Committee: Ann Underhill	Proposed: Ian Crisp	Kevin Bittlestone	Seconded: Jamie Watson	Elizabeth Littlewood		
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	<p>Sue Szablewski Heather Delaney</p> <p>Because of family commitments Sarah will not take over as Chair until September. Kevin will remain as Chair until then.</p>	
8.	<p><b><u>What do we want from the Society?</u></b></p> <ul style="list-style-type: none"> <li>- It was unanimously agreed that the annual meeting with a medical speaker was very important.</li> <li>- It was suggested that a meeting which involved young patients with FD would be a good idea.</li> <li>- There were comments that the web site was looking dated and should be easier to navigate around.</li> <li>- Several members expressed concern that we are not raising our profile among the medical profession, GP's especially. Suggestions were flyers or to approach drug companies for funding to produce pens etc. with details of the web site on.</li> </ul>	
9.	<p><b><u>Meeting Close</u></b></p> <p>Kevin thanked everyone for coming and the meeting closed at 3.40.</p>	
10.	<p><b><u>Date of next meeting</u></b></p> <p>Stanmore is successful because of the availability of medical speakers but we are aware that it is too far for some members. Next year's venue was not decided on.</p> <p>It was suggested that the 2012 meeting be arranged for a Saturday in late September or early October. We will advise all FDSS members as soon as the date and location have been arranged.</p>	

Draft minutes agreed by Chairman

Chairman:

Date:

Minutes confirmed by Committee

Chairman:

Date: