



Fibrous Dysplasia Support Society

MINUTES OF THE 2009 ANNUAL GENERAL MEETING

**Held at 10.00am on Saturday 31st October 2009
Venue – Express by Holiday Inn. Birmingham NEC,
Bickenhall Parkway, Birmingham, B40 1QA**

<p>1.</p>	<p><u>Present</u> Kevin Bittlestone (Chair) Sue Szablewski (Secretary) Jamie Watson (Treasurer)</p> <p>Frank Szablewski, Neil Buck, William Buck, Trisha Shelley, Graham Shelley, Leanne Shelley, Russell Morrison, Clair Wadey, Gary Wadey, Ray Cook, Sheila Cook, Heather Delaney, Isobel Dickson, Richard Mee, Gary Liversidge, Jane Liversidge, Ann Underhill, Franzesca Watson, Dave Watson, Elizabeth Littlewood, Cecil Lawrence</p> <p><u>Apologies</u> Ian Crisp, Karen Mikkelson, Eve Marie Griffin</p>	<p><u>ACTION</u></p>
<p>2.</p>	<p><u>Introduction</u> The chair started the meeting at 10.30am by introducing himself then welcoming all the attendees. He appreciated that many had traveled significant distances. He then suggested that those who were happy to do so introduced themselves and outlined their involvement with FD. Several people outlined their experiences and described one of their biggest problems as 'looking so normal that no one believes that you have a problem'. A recurring pattern of difficulty was in getting the right diagnosis. Hopefully FDSS will help by providing information to those with the condition.</p>	
<p>3.</p>	<p><u>Minutes of the Last Meeting</u> The minutes of the last meeting held on the 18th October 2008 were read. Frank Szablewski proposed that they be accepted as a true and accurate record and Elizabeth Littlewood seconded them.</p>	

4.	<p><u>Matters Arising</u></p> <p>Sue to contact Charity Commission for their advice on not having a fixed month for our AGM. The reason for possibly moving the month when we hold our AGM is that the meetings are Dependant on our ability to attract a medical speaker. Kevin asked all the group to provide the details of a medical contact who may be willing to attend one of our meeting.</p> <p>Survey to patients and medical groups on hold until we can assess reaction to our website.</p> <p>Ann to apply for a grant from Contact a Family.</p> <p>Franzesca has updated (October 2008) the FDSS list of medical specialists.</p>	<p>SUE</p> <p>ALL PRESENT</p> <p>ANN</p>
5.	<p><u>Chair's Report</u></p> <p>Kevin said that it was worth all the effort involved in setting up the meeting to see such a gathering present. Last year we had to cancel a meeting, which had no medical speaker, because of lack of support.</p> <p>The FDSS address list was now up to 81.</p> <p>Kevin thanked all concerned for the very generous donations in response to our fund-raising but fund-raising continues to be an on-going concern and further donations will still be required.</p> <p>The FDSS web site is now up and running and we anticipate that it will grow. He asked everyone to let Ann know of suggested changes.</p> <p>He advised everyone to continue to use the FDSOL site as it contains such a depth of experience into the condition.</p>	
6.	<p><u>Financial Report.</u></p> <p>Ann gave the FDSS financial status. To the 30th of October we have raised £1400.02 in donations and incurred expenses of £577.61. These expenses involved the room hire and lunch charges for today's meeting, the costs of setting up the web site and a two year hosting fee for it and the cost of copying the CD's from the FD Foundation 2007 convention.</p> <p>She again stressed that fund-raising was a significant issue for the society and urged everyone to do what they could to help.</p>	
7.	<p><u>Election of Executive Committee and Committee</u></p> <p>Neil Buck acted as stand in chair for these election.</p> <p>Chair: Kevin Bittlestone Proposed: Ann Underhill Seconded: Jamie Watson</p> <p>Secretary: Ann Underhill Proposed: Sue Szablewski Seconded: Kevin Bittlestone</p> <p>Treasurer: Jamie Watson Proposed: Kevin Bittlestone Seconded: Frank Szablewski</p> <p>Committee: Franzisca Watson Proposed: Kevin Bittlestone</p>	

	<p>Committee: Sue Szablewski Seconded: Ann Underhill Proposed: Kevin Bittlestone</p> <p>Committee: Neil Buck Seconded: Ann Underhill Proposed: Ann Underhill Seconded: Kevin Bittlestone</p> <p>Committee: Elizabeth Littlewood Proposed: Kevin Bittlestone Seconded: Jamie Watson</p>	
8.	<p><u>Web Site</u> Ann spoke briefly about the web site which went live on the 10th of October. Its address is http://www.fdssuk.org.uk and she urged people to log on to it as often as possible as it needs significant activity to work its way to the top of the Google search engine. We need it to be easy to find for the people looking for information on FD who don't know that we exist.</p>	<p>ALL PRESENT</p>
9.	<p><u>Dr Michael Davie Consultant Physician/Clinical Director of the Charles Salt Research Centre RJA Orthopaedic Hospital Oswestry Shropshire.</u></p> <p>After lunch Dr Davie gave a presentation on McCune Albright Syndrome with an emphasis on Polyostic FD. He spoke of the prevalence in the general population, skin pigmentation, endocrine involvement and the causes. This is not an inherited condition nor can it be passed on to your children.</p> <p>He spoke of the use of the TcMDP scanning to identify areas affected and of the affects of Phosphaturia (where the body excretes large amounts of Phosphate).</p> <p>He explained that FD is most commonly found in the lower limbs.</p> <p>He then went round the room answering questions.</p> <p>A real concern with surveys done on MAS/FD is the number of respondents. He had examples of charts created from 27 responses.</p> <p>At the end of the question and answer session Kevin expressed the gratitude of the group to Dr Davie for what had been a really informative and enlightening afternoon.</p> <p>Ann has agreed to send a survey questionnaire about the condition to all in the FDSS address book.</p>	

<p>10.</p>	<p><u>Meeting Close</u> There was some general discussion about the web site and the requirement for a map of where patients are and the need for a fund-raising section.</p> <p>Kevin again thanked everyone for coming and the meeting closed at 3.45pm.</p>	<p>ANN KEVIN</p>
<p>11.</p>	<p><u>Date of next meeting</u> The date and location of the next meeting are dependent on the medical speaker we obtain to address us but all will be advised in good time</p>	

Draft minutes agreed by Chairman

Chairman:

Date:

Minutes confirmed by Committee

Chairman:

Date: