



Fibrous Dysplasia Support Society

**MINUTES OF THE 2009 ANNUAL GENERAL MEETING**

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

<p>1.</p>	<p><b><u>Present</u></b> 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><b><u>Apologies</u></b> Ian Crisp, Karen Mikkelson, Eve Marie Griffin</p>	<p><b><u>ACTION</u></b></p>
<p>2.</p>	<p><b><u>Introduction</u></b> 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><b><u>Minutes of the Last Meeting</u></b> The minutes of the last meeting held on the 18<sup>th</sup> October 2008 were read. Frank Szablewski proposed that they be accepted as a true and accurate record and Elizabeth Littlewood seconded them.</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><b><u>Web Site</u></b> Ann spoke briefly about the web site which went live on the 10<sup>th</sup> of October. Its address is <a href="http://www.fdssuk.org.uk">http://www.fdssuk.org.uk</a> 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><b>ALL PRESENT</b></p>
9.	<p><b><u>Dr Michael Davie Consultant Physician/Clinical Director of the Charles Salt Research Centre RJA Orthopaedic Hospital Oswestry Shropshire.</u></b></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><b>10.</b></p>	<p><b><u>Meeting Close</u></b>  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><b>ANN KEVIN</b></p>
<p><b>11.</b></p>	<p><b><u>Date of next meeting</u></b>  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: