



MINUTES OF THE 2010 ANNUAL GENERAL MEETING

**Held at 10.00am on Saturday 16th October 2010
Venue – Seminar Room 1, RNOH, Brockley Hill, Stanmore,
Middlesex, HA7 4LP**

<p>1.</p>	<p><u>Present</u> Kevin Bittlestone (Chair) Ann Underhill (Secretary)</p> <p>Sue Szablewski, Frank Szablewski, Ray Cook, Sheila Cook, Heather Delaney, Isobel Dickson, A Dickson, Alan Dickson, Kate Mee, Sarah Russell, Ian Crisp, Lisa Coates, Franzesca Watson, Dave Watson, Elizabeth Littlewood, Cecil Lawrence, Dr Aruna Jago-Brown</p> <p><u>Apologies</u> Jamie Watson, Val and Peter Hill, John Rouse, Gary and Jane Liversidge, Sharon and Darren Hall, Neil, Sarah and William Buck, Karen Mikkleson, Stephen McMurray</p>	<p><u>ACTION</u></p>
<p>2.</p>	<p><u>Introduction and Chair's Report</u></p> <p>Kevin started the meeting at 10.10am by welcoming all the attendees. He gave a review of the past year. The meeting at Ann's was cancelled through lack of interest but the web site has been productive in generating interest in the society. We now have 80 email addresses in the FDSS address book.</p> <p>He then thanked Sheila Cook for all the help she has given towards fund-raising for the society, Carole Unwin for raising £200 for us in The Great North Run, Elizabeth Littlewood and Aruna Jago-Brown for giving talks at the meeting and Ann for arranging it.</p> <p>He said that the web site was bringing us to the attention of a wider public as we have been approached both by Channel 4 and a reporter to see if anyone was interested in being featured in a program or article.</p> <p>Our web site has now moved up to the second page on a Google search and he is getting about two enquiries a month through it.</p>	

	Kevin would like to stand down as chair.	
3.	<p><u>Minutes of the Last Meeting</u></p> <p>The minutes of the last meeting held on the 31st October 2009 were read. Sue 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 was asked to be Medical Liaison to the group. She has asked for a job description for this role.</p>	KEVIN/SUE
5.	<p><u>Secretary's Report</u></p> <p>Ann told the group that little had been achieved in producing a 'Quality of Life' survey. She received 29 replies from the group on her initial 'are you prepared to do a survey' question. 28 were positive. Dr Davie then advised that we contact Involve, an NHS funded group, and they offered some advice but could not provide funding. Mike Collins nurse, at the NIH, has done such a survey. Ann will contact her.</p>	ANN
6.	<p><u>Treasurers Report.</u></p> <p>Ann told the group that Jamie was unable to present the report but that he had provided two financial reports of our finances. The first for the period 15th April 2008 to 31st March 2009 and the second for the year ending 31st March 2010.</p> <p>Since the group was founded our biggest expenses have been setting up the web site and holding our annual meetings.</p>	
7.	<p><u>Election of Executive Committee and Committee</u></p> <p>Sue Szablewski acted as stand in chair for these elections.</p> <p>Chair: Kevin Bittlestone Proposed: Elizabeth Littlewood Seconded: Lisa Coates</p> <p>Secretary: Ann Underhill Proposed: Elizabeth Littlewood Seconded: Kevin Bittlestone</p> <p>Treasurer: Jamie Watson Proposed: Elizabeth Littlewood Seconded: Franzesca Watson</p> <p>Committee: Franzesca Watson Proposed: Kevin Bittlestone Neil Buck Seconded: Ray Cook Elizabeth Littlewood Sue Szablewski Heather Delaney Sarah Russell Lisa Coates</p>	

8.	<p><u>AOB</u></p> <p>It was suggested that we ask members for a subscription as a membership fee could aid our application for funds. If we did Sue believes that we need to change our constitution. Lisa will investigate this with the Charity Commission.</p> <p>Kevin suggested that on a set date each year we ask members for a small donation, say £10, in the belief that they may be happy to contribute.</p> <p>Ian suggested adding PayPal to our web site. Kevin will investigate.</p> <p>Kevin asked attendees to let us know of their achievements which can be published on the web site.</p> <p>We need to make specialists aware of our web site and meetings.</p> <p>Lisa suggested that we set up an entry on Facebook. Kevin will send her his FD email contacts list after first asking if any members wish to be excluded.</p> <p>It was agreed that we need a charity number as even simple fund-raising is hampered without one. Ann to contact Charity commission.</p>	<p>LISA</p> <p>KEVIN</p> <p>KEVIN</p> <p>ALL PRESENT</p> <p>ANN</p> <p>LISA</p> <p>KEVIN</p> <p>ANN</p>
9.	<p><u>Elizabeth Littlewood</u></p> <p>Finding the Answers: Our journey in MAS/FD</p> <p>Elizabeth told us that her daughter has McCune Albright Syndrome (MAS) which comprises a triad of conditions – café-au-lait pigmentation, FD and endocrine dysfunction (including precocious puberty) which is caused by a defect in embryonic development. The symptoms are more severe the earlier this defect occurs. She told us that there is a genetic test, which was developed at Leicester University, which tests a specific gene to prove that you have MAS. She was asked how easy it is to get this test done and replied that Great Ormond Street are using a laboratory in London. She believes that an endocrinologist would either know where to get the test done or could easily find out.</p> <p>Elizabeth was concerned with her daughters’ early development and, using the Internet for her research, she was able to contact experts, find support and details of the latest research, regardless of geographical distance.</p> <p>She emphasized here the benefit of an early diagnosis and her message to other parents is that they should trust their instincts as they are dealing with a very rare condition which few doctors have seen.</p> <p>The NIH (National Institute of Health, in Washington, USA) advised her to join a new trial in the UK and she was referred to Great Ormond Street Hospital and her daughter started the trial at three. She attended a conference organized by the MAGIC</p>	

	<p>Foundation in Chicago where she met doctors who had treated MAS and 40 other families with MAS children.</p> <p>Four years ago her daughter started a second clinical trial, again at Great Ormond Street, which is proving to be more successful. She handed out a list of 20 websites which she has found useful in her research for information about the condition and it is attached with these minutes.</p>	
10.	<p><u>Dr Aruna Jago-Brown.</u> The FD Diet – Myths and Truths</p> <p>Aruna advised that we should keep our weight down and be BMI perfect and find a form of exercise that suited us.</p> <p>She indicated which foods were high in calcium, vitamins A, D and K.</p> <p>She advised that we should cut down both on caffeine – alcohol, tea, coffee and chocolate – and on smoking.</p> <p>She said that with FD our hormone and calcium levels change all the time and that we should have our thyroid function checked every year.</p> <p>She concluded by saying that there is no such thing as a perfect diet for FD but recommended the ‘eat well’ plate as promoted by the Food Standards Agency.</p>	
11.	<p><u>Dr Richard Keen.</u> Director of the Metabolic Bone Disease Unit at the RNOH, Stanmore and honorary senior lecturer at the Institute of Orthopaedics and Musculoskeletal Science, University College London.</p> <p>Dr Keen started his presentation by outlining the history of the RNOH, Stanmore from its foundation in 1905.</p> <p>His talk was focused on the use of bisphosphonates in the treatment of FD but he also made several general recommendations.</p> <p>The main focus of bisphosphonates is to alleviate the pain associated with FD although French studies have shown that with their use the FD lesions have become more calcified and, therefore, stronger.</p> <p>There is a question over how long to treat patients with bisphosphonates as it is not yet really understood for how long they continue to work and specialists are currently trying to discover the optimum length of treatment.</p> <p>Dentists are concerned about treating patients taking bisphosphonates because of reports, in a very few cases, of osteonecrosis following dental work in patients on bisphosphonates. Dr Keen said that this had occurred in patients who had primary or secondary bone cancer. A</p> <p>He advised that we all take a vitamin D supplement or spend 20 minutes in the sun each day.</p> <p>Dr Keen’s talk was followed by a lively question and answer</p>	

	<p>session:</p> <p>There is no count of the incidence of FD.</p> <p>A simple blood test cannot detect FD.</p> <p>If ALP is changing it may reflect more FD activity.</p> <p>Permanently raised ALP – if no pains then leave it alone.</p> <p>Dr Keen happy to see patients referred by their GP.</p> <p>In females FD seems more prevalent when they are younger.</p> <p>Treatment for cancer affects FD too.</p> <p>Difficult to show that FD patients are more susceptible to osteoporosis.</p> <p>Best type of exercise to maintain muscle strength: - 20 – 30 minutes of aerobic exercise, cycling, swimming. Load bearing activity like skipping or jogging, a brisk walk or Pilates training with bands. Ballet is very good.</p> <p>The optimum age for a full body scan in girls, best to wait until menstruation starts but Stanmore provide a full body MRI scan which is radiation free.</p> <p>Do we need endocrine tests? For longer term surveillance of condition we should see an endocrinologist.</p>	
12.	<p><u>Meeting Close</u></p> <p>Kevin again thanked everyone for coming and the meeting closed at 3.45pm.</p>	
13.	<p><u>Date of next meeting</u></p> <p>Stanmore was so successful that we will try to meet there again next year.</p> <p>The date of the next meeting is dependent on the medical speaker we obtain to address us but we will try for a Saturday in October 2011. We will advise all FDSS members in good time</p>	

Draft minutes agreed by Chairman

Chairman:

Date:

Minutes confirmed by Committee

Chairman:

Date: