



Minutes of the 2013 Annual General Meeting

**Held at 10am on 19 October 2013 at the Royal National Orthopaedic Hospital
(RNOH), Brockley Hill, Stanmore, Middlesex, HA7 4LP**

1.	<p><u>Present</u> - Sarah Russell (Chair); Ian Crisp (Treasurer); Lisa Scoates (Secretary) Ismail & Julia Refet; Kate Mee; Tracey & Marcus Underwood; Heather Delaney; Isabel and Andrew Dickson; Patricia Jones; Mark & Millie Pickford; Jamie & Charlotte Watson; Ray & Sheila Cook; Mandy Fender; Jon Price; Edwin Aslin; Kevin Bittlestone & Diane Law; Barbara Almond; Paul White; Elizabeth Littlewood; Ann Underhill; Peter McBride; Danielle Morland</p> <p><u>Apologies</u> -Bethan Jones; Caroline Robson; Lucy Crosby; Elaine Walker</p>	
2.	<p><u>Welcome and Introductions</u> – Kevin welcomed everyone to the meeting and introductions took place.</p>	
3.	<p><u>Dr Paul Arundel, Consultant in Paediatric Metabolic Bone Disease, Sheffield Children’s Hospital</u> – Dr Arundel is a Consultant in Paediatric Metabolic Bone Disease at Sheffield Children’s Hospital. Dr Arundel explained that he proposed to give us a perspective of what he does and his involvement with other professional specialists at Sheffield.</p> <p>Dr Arundel did his specialist training in Leeds, where he gained experience in treating children with bisphosphonates, and explained that most MAS/FD specialists are Endocrinologists. He has worked with Dr Nick Bishop at Sheffield for six years where he works mainly with children with osteogenesis imperfecta (brittle bone disease). At Sheffield each child is involved with a team of specialists including:- Endocrinologists, surgeons, psychologists, social works, occupational and physio therapists.</p> <p>Dr Arundel sees few MAS patients but MAS is not treated as a ‘rare’ disease.</p> <p>He then gave an overview of FD/MAS. These conditions are caused by a genetic mutation, a problem of signalling within the cells. The severity of the disease is determined by how early in embryonic development this problem occurs. The disease encompasses Fibrous Dysplasia instead of normal bone cells, pigmentation and hormonal issues which can give you problems with your thyroid etc.</p> <p>Some people may have just one area of FD, others have many and</p>	

some, about one in twenty, can experience excessive hormonal problems.

FD is a descriptive term for problems in the bone and MAS implies excessive hormone production. There are lots of different centres across the country with complete teams and an established protocol for treating MAS patients. Patients present with varied conditions but paediatricians only look at children, some of them very young. His first question is in establishing the extent of the FD, after the age of six the likelihood of new bone lesions lessens then he would assess the potential hormonal problems. He would use diagnostic bone scans and watch areas of FD in cranio-facial bones more closely.

Dr Arundel took questions while continuing with his talk.

Q. Does FD stop growing in an adult of 34?

A. A doctor would try and give probabilities of what might happen but these can vary with each individual.

As a doctor the question is – is it worth knowing that your child has cranio-facial disease?

Q. A child patient has been told to leave cranio-facial FD alone but still get it checked. What would he advise?

A. That would probably be his advice too but would refer the patient to a Cranio-facial surgeon with many years' experience. Dr Arundel concerned too about levels of radiation with MRI scanning.

A big issue with young patients is the follow on care for young adults, a concern that Sheffield is trying to address with the setting up of a transition clinic which will provide care for 18-25 year olds. Within the NHS there is an increasing awareness of this issue and a willingness to address it.

Q. Patient spent a long time having physio and had significant problems getting a bone scan.

A. General awareness of bone problems is low.

Q. Does bisphosphonate stop bone pain?

A. Not necessarily but this is where the team may help in co-ordinating medical treatment with bisphosphonates for pain.

Q. Will bisphosphonates strengthen bone?

A. Possibly, but the main reason for their use is pain relief.

Pain is possibly caused by the number of nerve endings in FD areas. Giving bisphosphonates is sometimes used to prevent fractures, this is not proven but it's worth a try. This is now 20 years of experience in using bisphosphonates. Common side effects are flu like symptoms. Concerns with bisphosphonates over osteonecrosis (dead tissue in the

jaw) is generally seen in elderly patients and not children. He advised patients with bad teeth to get the treated before taking bisphosphonates. Bisphosphonate is not given to every patient, the specialist team decide who it will benefit. There is a new treatment, DESONUB, which seems to be effective in stopping pain in FD. He advised women who want to get pregnant to discuss with their doctor what drugs to take through their pregnancy.

Q. What doses for children?

A. Small doses, the decision is made on the extent of the disease after s study for surgical cause of pain.

Q. How much cranio-facial pain do you see in children?

A. Not much and he himself has never used bisphosphonates for cranial-facial pain.

Q. Why do symptoms begin when they do?

A. Bone is changing through life so there is no real reason. Generally FD is less active in adulthood.

Q. What is the role of vitamin D?

A.MAS girls are vitamin D deficient but half the population are vitamin D deficient. There is an interplay between calcium absorbs ion and vitamin D deficiency. He advised taking a vitamin D supplement and getting lots of sunshine.

Q. Do we need blood tests to check our levels of minerals?

A. Probably not, as long as no other risk factor.

Q. Should a patient with FD be monitored?

A. It would be a good thing to be monitored but not necessarily blood tests/scans. We need guidelines.

Q. Is it hereditary?

A. There is no way it can be inherited. It is completely random.

A new commission has said that MAS/FD child patients should be seen by specialist groups. Adult care is not something that he is familiar with. Dr Kassim Javaid is working to set up a database of FD patients within this financial year. He said that families sometimes struggle with co-ordination of care, terminology and managing uncertainties when doctors are unable to be specific about possible outcomes. He suggested that the FDSS as a group should think about what we should lobby for. For example, the brittle bone society is lobbying for medical support and extra funding. He recommended that we contact the chair of the brittle bone society (Patricia Osbourne) to help us decide on our priorities and how to take them forward.

	<p>Q. How rare is FD.</p> <p>A. FD is 1 in 30,000. MAS, there is no figure.</p> <p>Q. What should be the frequency of bisphosphonate infusions?</p> <p>A. b40% will see an immediate benefit. Others will see a gradual improvement over a year. Sometimes there is no improvement. Bisphosphonates are a drug that needs to be tailored to the individual.</p> <p>Q. Can a GP prescribe bisphosphonates?</p> <p>A. No, you need a hospital and endocrinologist to prescribe. Sometimes chronic pain teams can be helpful.</p> <p>Sarah thanked Dr Arundel on our behalf.</p>	
4.	<p><u>Minutes of the last meeting/matters arising</u> – There were none and minutes were agreed.</p>	
5.	<p><u>Secretary's Report</u> – The society has now got 136 members registered. Up from last year's membership of approx 119. Several more recent requests from people to be added to the mailing list have come through FB in the last few weeks as posts about the meeting have gone up. Again people are requesting a meeting up north as they are unable to travel south to the RNOH.</p> <p>Ian and I have spoken to, and offered support to several people this year (either on the phone) or thru FB as either their children/close relatives i.e nephew have recently been diagnosed with FD (lady from N.I) This week another 2 people have asked for support thru FB page. I have said I will ask members via an email who is willing to have their details passed onto these people in order for them to contact them to chat.</p> <p>Facebook Page – We have now got 233 likes, compared to 149 at this time last year. People are finding the FB page mainly through Google but also via our own website. 151 UK-based followers, 30+ from USA and the rest from 28 other countries including Canada, Australia, Norway, India and even 1 follower based in the Bahamas! 74% women and 26% men.</p> <p>Several requests through FB for updated list of consultants/specialists in FD.</p> <p>EasyFundraising – We now have 23 registered to raise funds for FDSS UK. This is compared to 8 people registered at this time last year. Total raised to date is £17.20. 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>	
6.	<p><u>Treasurer's Report</u> –</p> <p>Ian took over as treasurer last year and during that year he has moved twice, with all the paperwork from the FDSS account still waiting to be</p>	

	<p>unpacked).</p> <p>In March 2012 the Society had £3400.05 in its account.</p> <p>With the money that Ian paid in after the 2012 FDSS AGM and various fund raising efforts in September 2013 the Society had £4684.64 in its account.</p> <p>The fact that we now have a Charity number helps with the fund-raising. Ian would like to create an FDSS Thank you letter to send out to all those who donate to the Society. We also need an FDSS Sponsorship form.</p> <p>Accounts were approved.</p> <p>Proposed Sarah Russell</p> <p>Seconded Elizabeth Littlewood</p> <p>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.	<u>Chair's Report</u>	
8.	<p><u>Election of Executive Committee/Committee</u> – The following were elected as members of the committee to the positions of: -</p> <p><u>Co-Chairpersons</u> – Ann Underhill/Sarah Russell</p> <p>Proposed by: Lisa Scoates. Seconded by: Kevin Bittlestone</p> <p><u>Secretary</u> – Lisa Scoates</p> <p>Proposed by: Ian Crisp. Seconded by Kate Mee</p> <p><u>Treasurer:</u> Ian Crisp</p> <p>Proposed by: Paul White. Seconded by Elizabeth Littlewood</p> <p>Other members of the committee are: -</p> <p>Kevin Bittlestone; Heather Delaney; Elizabeth Littlewood; Jamie Watson</p>	
9.	<p><u>Discussion time</u> – The Rudy Study was discussed. This is to be led by Dr Kassim Javaid. Information will be sent to members as and when it is available. Ann Underhill will be</p> <p>There was further discussion about the website and it was suggested that it could be updated.</p> <p>The idea of using an alternative, more central location was discussed. It was agreed to source an alternative to see if this attracted further members.</p>	
10.	<u>Close</u> – The meeting was closed by Kevin at 1530.	