



Fibrous Dysplasia Support Society

Minutes of the 2014 Annual General Meeting

Held at 10am of 11th October 2014 at the Lecture Theatre, Nuffield Orthopaedic Centre, Windmill Road, Headington, Oxford OX3 7HE

<p>1.</p>	<p><u>Present -</u></p> <p>Ann Underhill; Cecil Lawrence; Ed Aslin; Elizabeth Littlewood; Kevin & Diane Bittlestone; Ian & Lisa Crisp; Jon & Mandy Price; Laura & Michelle Gray; Louise Loadsman; Mandy & Jessica Lloyd; Marcus Underwood; Tracy Underwood; Mike Dove; Peter McBride; Sue, Dave & Emily Aston; Tracey & Marcus Fenech; Jamie Watson</p> <p><u>Apologies -</u></p> <p>Paul White; Jacqueline Kiddle; Lisa Scoates, Sarah Russell</p>	
<p>2.</p>	<p><u>Welcome and Introductions –</u></p> <p>Meeting was opened by Ann who introduced Dr Javid.</p>	
<p>3.</p>	<p><u>Dr Kassim Javid MBBS, BMedSci, MRCP, PhD</u></p> <p><u>University Lecturer in Metabolic Bone Disease</u></p> <p>Dr Javid presented RUDY : (Rare Decease UK Study)</p> <p>Why RUDY? This is because most rare deceases are under studied, Doctors and Consultants can only make their diagnosis and treatments on previous experience and known information: With limited patient base, as is the case with rare deceases, this base of information and can be restricted.</p> <p>A rare decease is classified as being less than 1 in 5000. The initial conditions included with RUDY are Vasculitis, Ostegensis Imperfecta, XLH and Fibrous Dysplasia.</p> <p>Often Doctors/Consultants do not see patients with Fibrous Dysplasia, which can result in the condition being misdiagnosed.</p> <p>Rudy is patient driven – Aiming to involve the participants and enable whole medical history mapping.</p> <p>RUDY is a Government Funded Initiative to overcome misunderstanding, focus research into the effects of rare deceases, to improve understanding and build a relation with the medical industry</p> <p>RUDY is set to collate information, identify differences, try and establish</p>	

potential reason for the decease, why is there pain? What helps with coping?

Because it is patient driven this gives the researches a progressive and focused approach.

Because of the nature of rare conditions it is difficult to locate patients with relevant deceases or conditions.

RUDY is online in all formats, giving easy access and simple means to get involved. The extent of who you much you want to be involved is up to the participant – you can enter as much or as little as the patient feels best suit them. Dynamic consent allows for opting in and out as suits.

All information is held encrypted on a secure server, with patient information only being available to the participant and an administrator: It will not be possible to identify a patient from the entered data.

The initial sign-up process is completed online, which is follow up by a phone call to screen applicants and a series of online questionnaires. Medical examinations are generally carried out at main hospitals due to cost limitations, these are located throughout the country.

Within RUDY there are various committees, these are in place to ensure compliance in legal and ethical issues.

Dr Kassim Javaid then went on to discuss how RUDY would benefit those with Fibrous Dysplasia.

It has often been difficult for those with FD to been seen by multiple doctors or consultants, RUDY will have the facility to enable patients to access a full summary of all their entered information, with ease of access to their medical history this could assist in future or on-going personal medical treatment.

It is not fully understood why FD is painful, although study has found evidence that abnormal bone growth can also cause abnormal nerve growth. The holistic approach to the study may identify cause and effect that could be otherwise missed.

The level type and intensity of pain arising from Fibrous Dysplasia is as varied as the condition itself. RUDY requires those with all levels to ensure a balanced approach is maintained.

RUDY will provide a centre of core base of reliable database from which Fibrous Dysplasia patients can call upon.

Member of FDSS are encouraged to become involved.

Further information can be obtained at www.rudystudy.org

<p>4.</p>	<p>Dr Kassim Javaid opened the floor to questions:</p> <p>Q. What ages are included?</p> <p>A. All ages including children</p> <p>Q. How many are required?</p> <p>A. The more that that is entered into the study programme the better and more reliable the information gained.</p> <p>Q. How many are currently enrolled in RUDY?</p> <p>A. 143, only 3 have Fibrous Dysplasia: As previously noted this small number limits the information available.</p> <p>Q. What happens if I have no idea what or where my records are?</p> <p>A. RUDY is flexible enough to include what you information you have.</p> <p>Q. What about accessing my medical records held at a private hospital?</p> <p>A. Private hospitals are duty bound to release your medical records they hold upon request.</p> <p>Q. What happens if there is discrepancies in the medical history? There has been experience where something was diagnosed as one thing before being confirmed as Fibrous Dysplasia etc. ?</p> <p>A. The medical committee monitors the information submitted and can filter or flag up what appears as incorrect or conflicting information.</p> <p>Q. How do you calibrate the level of pain as one person can register it differently to another?</p> <p>A. The questionnaires are relative and formulated to pick up changes of a person's current level of comfort, discomfort or pain.</p> <p>Q. How is RUDY funded?</p> <p>A. RUDY is currently funded from Government central funding, National Institute of Health Research (NIHR), grants and hospital funding. However, it is intended that the medical industry will be bought on board, gaining the interest of Industry sector is considered beneficial as this would give access to a greater level of additional research funding.</p> <p>Q. How long is the existing funding secured?</p> <p>A. Funding is current is secured to 2017, with a five year window to crack a main answer to show the importance of the study.</p> <p>Q. If during a medical examination an incidental finding is found what happens?</p> <p>A. There are mechanisms in place to deal with this. The patient will be informed.</p>	
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	<p>Q. If I want to commit to RUDY what should I allow?</p> <p>A. Medical tests take about half a day, often less. The questionnaires are carried out online and can be done remotely on a computer, tablet, or smart phone.</p> <p>The locations of the test have been based designated hospitals. It is not possible for this to be carried out at local doctors surgeries due to the cost of transferring the information and test results back to RUDY</p> <p>Q. It has been found that when I attend a new doctors or hospital often spend time going through everything all again and trying to explain my condition, will RUDY help?</p> <p>A. Yes, the 'My Copy' section will be accessible to provide a summary of the individual's condition and medication.</p> <p>Q. Do Bio-phosphates work?</p> <p>A. They have been known to help but there can be side effects, sometimes it works, sometimes it doesn't. The only in depth study is currently being carried out in France but is currently inconclusive.</p> <p>Q. Do the tumours spread? Can Soft Tissue tumours result?</p> <p>A. Yes, it can happen, although it is rare it can occur. There are instances where patients are late diagnosed, which has meant the condition may have got a lot worse and have become more difficult to treat than if it had been picked up earlier. RUDY is trying to establish identifiers.</p> <p>Q. I have been from one Doctor to another, how do I know I am being seen by the right person?</p> <p>A. Conditions are designated as common or rare. RUDY will try and identify sign posts to help control who people see and where they are sent.</p> <p>Q. Does RUDY have contact outside the UK?</p> <p>A. Yes, currently there is contact in Europe and America. In America the study group generally require the patient to have an extreme/serious level of condition, which means the lesser cases are missed.</p> <p>Q. Can Fibrous Dysplasia get worse? Can it spread?</p> <p>A. It can change, but unfortunately, there is no confirmed answer.</p> <p>Q. How many times will you be scanned?</p> <p>A. About every two years is normal, but if there are concerns this may be increased and include other types of scans or tests.</p>	
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5.	<p><u>Break</u></p> <p>Hunt the lunch game played ☺</p>	
6.	<p><u>Minutes of last meeting / Matters arising</u></p> <p>Minutes of last meeting were agreed.</p>	
7.	<p><u>Secretary's report –</u></p> <p>Apologies from Lisa, Will be issued after the meeting, report given by Ian</p> <p>Would like to have photos and details placed onto our Facebook page.</p> <p>The use of Easy Fundraising by members and would be good for FDSS, especially over the Christmas period – a small amount is given to the group with each online purchase.</p>	
8	<p><u>Treasurer's report –</u></p> <p>Ian confirmed there is currently £4880.66 within the FDSS account.</p> <p>FDSS has a charity number but does not meet the requirement to become a registered charity.</p> <p>It was proposed to register for 'Just Giving' at a cost of approximately £18 per month. After discussion was agreed that this could be beneficial to the group</p> <p>Payment to the FDSS can be via bank transfer – Ian to be contacted for bank details, or by cheque.</p> <p>There were question about other ways to donate, suggestion to include a 'Donate' button on the website</p>	
9.	<p><u>Chair's report –</u></p> <p>Congratulations to Kevin and Diane who were married on the 26th September this year, and wish them all the best for the future, this news was warmly welcomed by all. . .</p> <p>Ann confirmed numbers have increased.</p> <p>Website can be updated, but requires information and details to be passed to Ann, and would welcome any news stories, suggestions or recommendations.</p> <p>Similarly, the FDSS Facebook requires posts to maintain of interest.</p> <p>Ann echoed that members should be encouraged to become involved with RUDY as this will be beneficial.</p> <p>Next meeting scheduled for the 3rd October 2015 (Saturday) subject to confirmation – Venue to be confirmed.</p>	

<p>10.</p>	<p><u>Election/re-election of committee –</u></p> <p>The following were elected as members of the committee to the positions of: -</p> <p>Ann Underhill was re-elected as chair</p> <p>Ian Crisp was re-elected as treasurer</p> <p>Lisa Scoates stepped down as Secretary and Edwin Aslin was elected</p> <p>Heather Delaney, Sarah Russell, Elizabeth Littlewood, Kevin Bittlestone, Jamie Watson and Lisa Scoates would like to remain on the committee – Agreed.</p>	
<p>11.</p>	<p><u>Discussion time –</u></p> <p>It was thought that for future meeting sticker / name badges would be good for future meetings</p> <p>Introductions were carried out, with each person giving a brief description of themselves and how Fibrous Dysplasia has affected their lives.</p> <p>This time due to Dr Kassim Javid's commitments the introductions were not carried out at the beginning of the meeting. It was felt, especially by new members, that they should be carried out earlier so people can know who are present and get a feel of the group.</p> <p>Peter McBride had been told that the bone growth would 'burn itself out with age' but this did not happen. Others reported similar incorrect comments and diagnosis, this was felt to be not uncommon.</p> <p>Pain management Fibrous Dysplasia appeared to be the main topic of discussion, with treatments and mediations varying from one person to another.</p> <p>The way people were told about having Fibrous Dysplasia and age at which the diagnosed varied. This ranged from some members identified at infancy and others in later life – and all ages between.</p> <p>Who you are seeing remains a big issue – A good Doctor who understands makes a difference to the level and quality of your treatment. Many members reported having been passed from one Doctor to another and of having been initially misdiagnosed.</p> <p>It was generally agreed that being able to meet others with Fibrous Dysplasia was a real support. There may be a way to being able to have with the website or Facebook a facility to make contact and find out where people are located and the potential to meet.</p> <p>This would need to be carefully controlled and personal information and contact details should not be openly available – This will be investigated.</p>	

	<p>Ann questioned how people would feel about being linked up? It was generally agreed that it would be good but open contact would be risky.</p> <p>The concern about Fibrous Dysplasia being inherited was again raised, with some members having been told it could: This is not possible, there is no evidence that it can be passed down the generations.</p> <p>The concerns about the change in treatment of children once they reach sixteen was raised, this remains a problem. There have been cases where the continued care from child to adult was not fluid and feelings of being left out and having to start again reported by a few.</p> <p>When a child is diagnosed with Fibrous Dysplasia the parent should always be present when the child is informed. Better 'child friendly' literature should be made available.</p> <p>Some members have reported reoccurrences and tumours growing back from areas where they have been removed. This contradicts some of the statements from Doctors and medical reports.</p> <p>The suggestion of sub-meeting in other parts of the country was raised, this would allow others who are unable to travel to attend and also more than one meeting year. This was agreed as being possible but would require some planning and a few logistic problems – Knowing where people are located would help in this.</p> <p>The American FD Facebook site has continuous comments, post and conversations from around the world. Some of the FDSS members are also part of this group. How do we raise the profile of the UK based FDSS Facebook?</p> <p>Not everyone uses Facebook – the group should look at alternative platforms for discussion and forums. Maybe a printed Newsletter.</p> <p>What should FDSS spend the charity money on? It was suggested that it could be used to fund the proposed additional meetings, pay for a guest speaker (reasonable expenses?) or to provide a recreational outing for the younger members.</p> <p>Concern was raised that a meeting without a guest speaker may not attract sufficient members to be worthwhile. Previous meeting have been attended by approximately 20-30 although numbers have increased over the past years.</p>	
	Round-up/close – Ann Underhill	