



## **Notes from the FDSSUK Annual Meeting**

**Saturday 17th November 2018 at**

**Birmingham Children's Hospital, Steelhouse Lane, Birmingham, B4 6NH**

Our first speaker of the day was Professor Nick Shaw who gave a presentation on - Overview of Fibrous Dysplasia in Children, Management and Transition from Child to Adult Services. Professor Nick Shaw is a Consultant Paediatric Endocrinologist at Birmingham Children's Hospital.

Professor Shaw gave a brief description of McCune Albright Syndrome and Fibrous Dysplasia and showed us some slides on the gene mutation and some examples of how the bones, hormone glands and skin can be affected by the disease.

He talked about types of treatment that can be given such as intravenous Bisphosphonates and Denosumab injections.

He also spoke about the transition from children to adult services. At Birmingham Children's Hospital they have a Ready Steady Go system, where they put a support plan into place for the child and a series of questionnaires for the child to complete throughout the process. The child will be supported throughout the transition period to help them cope with everyday life including education, work and relationships and prepare them for adulthood with a rare disease.

Dr. Kassim Javaid was the next speaker to make a presentation on – Overview of Fibrous Dysplasia in Adults, Common Myths and Misunderstandings. Dr. Javaid is a Consultant in Metabolic Medicine at Oxford University Hospitals and he has a special interest in FD/MAS and other rare diseases.

Dr. Javaid began his presentation with some statistics about the different types of pain that are associated with Fibrous Dysplasia and McCune Albright Syndrome.

There was a discussion around Bisphosphonates and how often they should be given, the side effects and the regular checks that should be given to the patient during the treatments. There was also a discussion about vitamin D checks.

Dr. Javaid showed us some information on the clinical pathway that he has been working on with Dr's from other countries that are part of the FD/MAS International Consortium. This is a document that can be used by Dr's all over the world to improve the care and treatment of Fibrous Dysplasia and McCune Albright Syndrome. There is also a patient's check list section that patients can take to their appointments and show it to their Dr. There are many Dr's who have never seen a patient with this disease, so this checklist is there to help them. This pathway has now been launched and will be published in medical journals for Dr's to refer to when they are treating patients with the

disease. The clinical pathway and patient checklist will also be on our website for viewing when it is launched in the next few months.

The next guest speaker was Dr. Joseph Abbott with his presentation on - When to Consider Optic Nerve Decompression and Neurosurgical options. Dr. Abbott is a Craniofacial Ophthalmic Consultant Surgeon at Birmingham Children's Hospital.

He showed us some slides showing the different types of tests that are carried out on the eyes and he explained what each test is looking for. Some of these tests are not available at high street opticians as the machinery is only available in hospitals. He showed us scan results of a patient who had urgent optic nerve decompression surgery. He went through the scan in detail and then explained what procedure they carried out to repair the patient's vision.

Heather Ryan was the next guest speaker and she gave a talk on – Housing, Jobs and Benefits. Heather is a clinical nurse but has more recently taken the role of Regional Care Advisor at the Oxford Neuromuscular Service at The John Radcliffe Hospital in Oxford.

Heather began by explaining the different types of benefits that are available in the UK, the application process and the eligibility process. The benefits are Disability Living Allowance, Personal Independence Payment, Universal Credit, Attendance Allowance and Carers Allowance. Heather gave us tips on how to fill the forms in and the types of medical evidence that should be submitted with the forms and she explained the appeals and tribunal process.

She also recommends that patients contact their local Citizens Advice Service and local support organisations for help with appeals and tribunals.

Heather also gave advice on occupational therapy services and funding that can be obtained for adaptations and equipment for the home and the workplace.

There are some charities which will provide funding towards holidays for patients, carers and their families. One of those charities is Over the Wall and their website is [www.otw.org.uk](http://www.otw.org.uk)

One of our members Nish Rai shared his fundraising and awareness idea with us. He would like to arrange a worldwide swimathon for Fibrous Dysplasia/MAS, sometime next summer. He would like as many people to take part as possible and anyone that is interested can email him at [worldfdswim@gmail.com](mailto:worldfdswim@gmail.com) or go to our facebook page or website to find further details.

Our next Speaker was Dr. Shazada Ahmed who gave us a presentation on – Neurosurgery. Dr. Ahmed is a Consultant Ear, Nose and Throat & Skull Base Surgeon at The Queen Elizabeth Hospital in Birmingham.

He explained his role as a surgeon and the types of operations that he does on patients with skull based Fibrous Dysplasia. He works as part of a multidisciplinary team. He showed us some scans of a patient who needed urgent optical nerve decompression surgery and he explained how he entered through the patients nose to get to the skull.

He showed us some videos of his work, the operating theatre and he also showed us the types of amazing computer equipment and instruments that he uses during surgery.

Dr. Kassim Javaid then gave us an update on his Research work – The Rudy Study & James Lind Alliance Research Project.

He explained what the Rudy Study is and went through the website in detail. He showed us some of the data that has been recorded in surveys that patients have completed. There is now a diary that patients can use to record their fractures and medications.

Dr. Javaid has also been part of the James Lind Alliance Research project for Rare Musculoskeletal Diseases in Adulthood. A steering group made up of medical professionals, patients and carers worked together to create a list of the top ten priority questions that should be researched when dealing with rare diseases. The three rare diseases covered in the project were Fibrous Dysplasia, Osteogenesis Imperfecta and X-Linked Hypophosphatemia. He explained the stages of the project and went through the final ten questions with us. The final report has now been officially launched.

Our next speaker was Jane Freebody who gave a presentation on - Physiotherapy and Associated Treatments. Jane is a Specialist Physiotherapist at The Oxford Neuromuscular Service at The John Radcliffe Hospital in Oxford.

Jane showed us examples of different types of low impact exercise and stretches that can be done to help with movement. She also explained how small amounts of activity can be beneficial for the heart, muscles and mental wellbeing of a patient.

She showed us examples of group activities that are available through local authorities such as, walking groups, chair exercise groups and water-based exercises.

[www.remap.org.uk](http://www.remap.org.uk) is a useful website for us to look at. They specialise in adapting equipment for disabled people. You can refer yourself to this service.

There is also a GP exercise referral scheme [www.everyoneactive.com](http://www.everyoneactive.com) where your GP can refer you to a gym where they specialise in people with disabilities.

Our annual patient's day was finished off with an informal discussion and feedback session led by two of our Trustees, Heather Delaney and Sarah Russell. They are both patients. This was a chance for our attendees to share their experiences with each other. Some of the topics discussed were diagnosis, treatment and future care.