

Wilson's Disease Support Group Meeting & 4th AGM

Cambridge Rugby Union Football Club, 13 July 2014

This year's annual meeting of WDSG-UK attracted an encouragingly good turnout on a warm, slightly humid day in Cambridge. **Mary, Linda** and **Valerie** greeted the Group's members and friends as they made their way to the spacious surroundings of the Cambridge Rugby Union Football Club. We were especially pleased to welcome back **Charlie Watsham** accompanied by Biggles, **Emma Colcott** and her mum, **Lesley**, and **James Kinnier Wilson**. Also, we were delighted to meet **Bongkeun Jeon**, his wife and their beautiful 4½-year daughter, **Olivia**. You will recall in this year's *WDSG-UK Newsletter* Bon's account of the diagnosis and treatment of Olivia whilst on a family visit to South Korea in 2011.



Clinicians and scientists with a special interest in Wilson's disease who attended this year were **Dr John Walshe, Kay Gibbs, Dr Godfrey Gillett** (Northern General Hospital, Sheffield), Consultant Hepatologist **Dr Bill Griffiths** (Addenbrooke's Hospital, Cambridge) and **Professor Aftab Ala**, Consultant Gastroenterologist and Hepatologist at Frimley Park Hospital, Surrey.

Before lunch, there were talks on links that WDSG-UK has with two other groups: the **Wilson's Disease Network – UK** and **Rare Disease UK**. The **Wilson's Disease Network – UK**, an informal collaboration of clinicians and scientists with an interest in Wilson's disease, is an initiative of **Dr James Dooley** and **Professor Oliver Bandmann**. It has the aim of improving the treatment of patients with Wilson's disease in the four home countries by the creation of recognised Centres of Excellence for treating the disease. One of the other goals of the Network is to establish a UK Registry of patients with Wilson's disease, and **Jerry Tucker**, Vice Chair of WDSG-UK, has taken on the task of gathering the information and documentation required to compile this Register. **Jerry** briefly described how this work is progressing and urged WDSG-UK members to participate in the project. **Rare Disease UK**, a national alliance for people with a rare disease, was involved with the input, compilation and launch in 2013 by the UK government of the **UK Strategy for Rare Diseases**. **Alastair Kent OBE** is the Chair of Rare Disease UK and has a major role in liaising with UK health professionals and UK government in the implementation of the Strategy. We were therefore very pleased that Alastair was able to give us a first-hand account of his work with Rare Disease UK at our meeting.

After lunch, **Linda** was presented with a cake in recognition of a 'special' birthday and for the work she has carried out for WDSG-UK since she and **Caroline Simms** founded the Group in 2000. The afternoon's proceedings began with the formalities of the WDSG-UK 4th AGM, during which the current management committee was unanimously re-elected for the year 2014-2015 and was thanked for its work over the preceding twelve months. **Belinda Diggles** then presided over the WDSG-UK raffle, resulting in the depletion of prizes from a table previously overlaid with tempting bottles of wine, plants, chocolates and cosmetics. This year Belinda's raffle raised £150, and the Group's funds were then further enhanced by a donation from Univar Ltd of £1000, which **Anne-Marie** accepted on behalf of WDSG-UK from **Philippa Hoare** and **Sabrina Chowdhury** of Univar.



Susan Mollan, a Consultant Neuro-ophthalmologist at University Hospitals Birmingham, gave the third presentation of the day. Susan and her team are investigating a number of advanced imaging techniques as diagnostic tools in ophthalmology, and in particular the application of optical coherence tomography (OCT). OCT is a non-invasive technique, which can provide cross-sectional images of tissue structure on the micron scale *in situ* and in real time. Hence OCT can function as a type of optical biopsy and can be used as a powerful imaging technology for medical diagnostics. Susan has been using OCT for the examination of Kayser-Fleischer rings (an ophthalmic manifestation of Wilson's disease).

Insightful questions from the audience had been addressed to the three speakers during the day, and these continued with further questions to all the medical specialists present before the meeting concluded with the customary Group photographs taken by **Barry Diggles**.

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