



Wilson's Disease Support Group – UK Annual Meeting, 21st July 2013

It was good to see such a large turnout of WDSG-UK members for our annual meeting at the Cambridge Rugby Union Football Club in Grantchester Road amid the tranquil surroundings of the club's playing fields. **Linda** and **Valerie** welcomed the Group's members and friends, who this year included **Bianca Klimsa** (from Verein Morbus Wilson e.V., the German patient support group), **Ron Shaw** (who was diagnosed with Wilson's disease in the 1950s), and **Charlie Watsham** (& Biggles) from Lichfield, plus the many members who support our annual meeting year in and year out. A very special guest this year was the distinguished Assyriologist **James Kinnier Wilson**, who is the son of the neurologist, Samuel Alexander Kinnier Wilson.

Many clinicians and scientists who have a special interest in Wilson's disease were also able to travel to Cambridge – **Dr John Walshe** (accompanied by his daughter **Susan**), **Kay Gibbs**, medical geneticists **Dr Richard Sandford** (Addenbrooke's Hospital, Cambridge) and **Dr Oliver Bandmann** (Royal Hallamshire Hospital, Sheffield), the Group's medical advisers, **Dr Godfrey Gillett** and **Dr James Dooley**, and from the National Hospital for Neurology and Neurosurgery, Queen Square, London, the neurologist **Professor Niall Quinn**.

The morning's proceedings began with a welcome from **Linda** followed by a presentation from our Vice-Chair **Jerry Tucker** on the opportunities offered by the current reorganisation of the NHS for the development of specialised services for rare diseases. Jerry outlined the type of service that WDSG-UK would like to see commissioned by NHS England for the treatment of Wilson's disease and explained that the patients' voice and patients' support groups can play a key role in bringing these proposals to fruition. The morning session concluded with a talk by **Professor Quinn** on the early career of Samuel Alexander Kinnier Wilson at the National Hospital, Queen Square in the 1900s and a description of some of the patients reported by Wilson in his landmark 1912 paper published in the journal *Brain*.

Lunch was an opportunity for guests to mingle and also buy some of **Allie Johnston's** beautiful handmade cards that she and her mother, **Rita**, had brought down to the meeting from Edinburgh. The proceeds (£60.35) from the sale of the cards were generously donated by Allie and Rita to the Group. The afternoon began with the formalities of the WDSG-UK 3rd AGM, during which the current management committee was unanimously re-elected for the year 2013-2014. Some splendid prizes were on offer for this year's raffle, again organised by **Belinda Diggles**, which raised £120.00, and the Group's funds were then further enhanced by a donation from Univar Ltd of £1000, which **Mary Fortune** accepted on behalf of WDSG-UK from **Graeme Manley** of Univar.

This year another landmark paper on Wilson's disease was published in *Brain* – 'A genetic study of Wilson's disease in the United Kingdom', *Brain*, 2013, **136**, 1476-1487 – and we were particularly pleased to hear first hand from one of the co-authors of that paper, **Dr Oliver Bandmann**, about the findings and conclusions of this important study.

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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