

2015 Wilson's Disease Support Group – UK Meeting & 5th AGM

Cambridge Rugby Union Football Club, Sunday, 12 July 2015

Cambridge Rugby Union Football Club's HQ was again the venue for the annual meeting of the Wilson's Disease Support Group – UK. About 40 patients, their families and supporters, gathered to celebrate the 15 years of the Group's existence. We were particularly pleased to welcome three new members, **Katie Hibbard**, **Jamie Vaughan** and **Alicia Goss**, and to welcome back **the Jeon family**, with little **Olivia**, **Scott Walker**, and **Charlie Watsham**[†] accompanied by Biggles. We were also delighted to see the many Group members who regularly make this trip to Cambridge each year, including **Linda Asher**, **Jane Ridley**, **Helen Khan**, **Emma Collcott**, and **Anusha Joseph**. The meeting was enhanced by the presence of nonagenarians **Dr John Walshe** and **James Kinnier Wilson**, and the participation of clinicians **Dr Godfrey Gillett** and **Dr James Dooley**.

The meeting began with two short talks by **Rupert Purchase** and **Jerry Tucker**, respectively. Rupert described the colours of copper compounds in aqueous solution, and explained how we have adopted these colours for our new Group logo and in publicity material for the Group. Jerry reported on the new Rare Disease Centre at the Queen Elizabeth Hospital, Birmingham. Wilson's disease will be one of the diseases treated at the new Centre, which will provide one-stop clinics where patients (with their carers) can undergo pre-planned diagnostic tests and see all specialists and the multi-disciplinary team relevant to their care at one visit. Jerry also reported on progress with the Wilson's Disease Patient Register – UK, details of which will be made available to clinicians and patients at the Rare Disease Centre in Birmingham.

WDSG-UK was founded by **Linda Hart** and **Caroline Simms**, PhD in 2000. To mark this fifteenth anniversary, Linda and Caroline reminisced before lunch about the Group's early days, when the annual meeting was held in Nottingham, and the highs and lows of a meeting on Wilson's disease they both attended in Leipzig in 2001. The 15th anniversary was recognised during lunch with a cake decorated with fifteen lit candles, which, appropriately, our youngest member, Olivia Jeon, expertly extinguished.



After lunch, the **5th WDSG-UK AGM** saw the re-election of the current committee for a further year, followed by the customary raffle, which raised £116.00. The Group's funds were then further boosted by a donation of £2,000 from Univar presented by Graeme Manley and his colleague, Sabrina Chowdhury. Graeme briefly described a new initiative by Univar to produce an information leaflet for patients with Wilson's disease.

The meeting concluded with a question and answer session between the audience and the three consultant physicians present. Whilst stressing the need for Wilson's disease patients to take their medication regularly, Dr Dooley acknowledged this is not easy, and expressed his admiration for patients facing this task. Before dispersing, members expressed their appreciation to **Valerie**, **Linda** and **Mary** for organising the meeting, and making this get-together for patients and friends such a success.



Rupert Purchase, Chair WDSG-UK 2015-2016

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[†] Not long after writing this report, we received the very sad news of the death of Charlie. We all recognised the courage Charlie displayed in trying to overcome her illness, and we extend our deepest sympathy to Charlie's family and friends.