

2016 Wilson's Disease Support Group – UK Meeting & 6th AGM

Cambridge Rugby Union Football Club, Sunday, 24 July 2016

A warm July day saw the largest ever gathering of the Wilson's Disease Support Group – UK for our annual meeting at the Cambridge Rugby Union Football Club. Many new members of the Group were able to attend this year, including **George Fortune, Ellie Gurnett, Jean Turley, Parbinder Singh** and **Kam Kaur, Katy Quinlan, Marta Targowska** and the **Chicu** family. From Denmark, we were delighted to welcome **Marie-Louise Ottesen** and her mother **Lisbet**. Lisbet runs the WD Support Group in Denmark and was keen to make a connection with our Group.

It was also good to welcome back **Katie Hibbard, Alicia Goss, the Jeon family, Scott Walker, Emma Collcott, Anusha Joseph, Keith Pereira,** and **David Lin**. David, whose story appeared in this year's newsletter, had flown in especially from Taiwan to surprise us all!

Another surprise guest was the singer-songwriter **Danny O'Donoghue** accompanied by his sister **Victoria**. The meeting was further enhanced by the presence of **Kay Gibbs**, the nonagenarians **Dr John Walshe** and **James Kinnier Wilson**, and the participation of clinicians **Dr Godfrey Gillett** and **Dr James Dooley**, whose presence we always appreciate.

In his introductory remarks, **Rupert Purchase**, Chair WDSG-UK, reported the sad news of the deaths of two of our members in the past year – Jon Tarbin, who attended the 2014 meeting, and Charlie Watsham, who was able to be with us in Cambridge last July, but passed away shortly afterwards. On a more positive note, he presented **Katie Hibbard** with a prize for winning Valerie's ingenious WDSG-UK Dingbats competition, which was published and distributed with this year's Newsletter.

Jerry Tucker, Vice-Chair (WDSG-UK), summarised recent developments with the Wilson's Disease Patient Register – UK, and the involvement of the two rare disease centres in Birmingham with this project. The proceedings before lunch concluded with a presentation by three biochemistry students from Oxford University – **Andreas Hadjicharalambous, Sam Garforth** and **Shu Ishida** – on their novel idea for the treatment of Wilson's disease. In simplified terms, it is suggested that a genetically-modified gut bacterium, which can chelate copper, could colonise the gut microflora and thereby reduce the absorption of dietary copper, thus alleviating the organ-specific effects of copper in patients with Wilson's disease. The design of this bacterium and news of this Oxford initiative may be found at <https://oxfordigem2016.wordpress.com/>



Lunch was followed by the 6th **WDSG-UK AGM** and the election of the WDSG-UK management committee for 2016-2017, with **Caroline Simms** replacing **Linda Hart** as a committee member. Linda was presented with two garden-themed gifts in recognition of her many years' work on the committee and supporting patients. Rupert thanked members of WDSG-UK for the imaginative ways in which they have raised funds over the past year, before **Danny** and **Alicia** hosted this year's raffle, which produced a further £99 for the Group.

WDSG-UK Annual Meeting, Cambridge, 24th July 2016

The steep rise in the cost to the NHS of the price of trientine dihydrochloride imposed by the UK supplier Univar (600% in two years) has caused much concern to patients and clinicians. This meeting was therefore an opportunity for us to share these concerns. Opening a 30-minute discussion on trientine, Rupert summarised the current situation and mentioned that in the USA Valeant Pharmaceuticals has increased the price of both trientine and penicillamine to over \$20,000/100

capsules or tablets for each drug (November 2015 data). Options to challenge Univar are limited at present. There are initiatives by the UK government to examine the role of trientine in Wilson's disease, and WDSG-UK members are encouraged to sign an online petition to protest about Univar's price increase: <https://you.38degrees.org.uk/petitions/stop-pharmaceutical-companies-hiking-vital-drug-prices-unfairly>

The meeting concluded with a question and answer session between the audience and the three consultant physicians present. Questions on gene therapy, and UK genetic services for testing for Wilson's disease were raised for discussion.

Finally, as is our tradition, a Group photograph was taken before we dispersed into the afternoon sunshine. We hope members felt it was a useful and helpful day.

Rupert Purchase, Chair WDSG-UK 2016-2017

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