

First-ever UK birdshot patient day

Birdshot chorioretinopathy is a rare, poorly understood chronic, bilateral form of posterior uveitis that affects individuals of all ages and can lead to irreversible visual loss.

The Birdshot Uveitis Society (BUS) joined forces with medical professionals from Moorfields Eye Hospital NHSFT, Guys and St Thomas' NHSFT and Pitie-Salpetriere University Hospital, Paris, to cover topics such as: what is birdshot; symptoms, diagnosis and prognosis; tests and monitoring; current treatments; and latest information on birdshot, new trials, and research. The afternoon sessions were more patient focused, with Mike Brace CBE, Chief Executive of VISION 2020 (UK) speaking about how he coped with blindness and Phil Hibbert talking about how he came to set up the Uveitis Information Group, after he was diagnosed with uveitis.

A total of 126 people attended the day which was a huge success (as evidenced by the six-month evaluation) because it:

- Allowed learning across patients and professionals
- Informed about latest treatments and thinking
- Addressed patients' concerns through questions and answers
- Allowed networking, experimenting with low vision aids and learning about other services
- Expressing how it feels to have birdshot through art
- Established a large cohort of patients who gave their

views on research priorities, enabling a research network (BRN) to go forward and flourish

- Raised the profile of the disease.

Rea Mattocks of BUS said: "Feedback from patients showed an overwhelming view that it had reduced their sense of isolation and given them renewed hope for their futures."

A DVD of the day has been produced and has been distributed to eye departments across the UK. If you have not received your copy, please contact: birdshot@uveitis.net. A 5-minute DVD is available at: <http://birdshot.org.uk/6670>

The next birdshot day will take place in March 2012. Details will be posted on <http://birdshot.org.uk/patientday>. UK consultants interested in being a part of the Birdshot Research Network (BRN) are welcome to join the existing members of the BRN at 11am on Tuesday 18 October 2011 at Birmingham and Midland Eye Hospital (Organiser Prof Murray). Contact BUS at birdshot@uveitis.net for further details.

The next patient engagement day to be organised by the PPI team at Moorfields and NIHR-BRC is focused on glaucoma. The patient day will take place on 1 October 2011 at the Central Hall Westminster. Further information will be available from the "Events" section of the BRC website, www.brcophthalmology.org/events. All patients and healthcare professionals are welcome.

Miss Narciss Okhravi