

The National Birdshot Research network is a partnership between the NIHR, BUS and leading clinicians

**NHS** National Institute for Health Research



The National Birdshot Research Network is an affiliation of interested clinicians and patients who are committed to developing a new national research strategy for this sight-threatening condition that affects an estimated 500 patients across the UK.

Fundamental questions surround birdshot chorioretinopathy, ranging from issues regarding its aetiology and pathogenesis to practical clinical issues such as how best to monitor the condition, optimal therapeutic regimes and impact on quality of life.

It is in response to these challenges that the National Birdshot Research Network has been formed. It is a gathering of the uveitis community, comprising both interested UK patients (represented by the Birdshot Uveitis Society) and leading ophthalmologists and ophthalmic scientists in the field. By working together, we believe that we can make real progress in our understanding and management of this disease.

A key foundation of this collaborative venture is the establishment of a National Birdshot Bio-Resource Centre (biobank) which will act as a central repository for patient data and clinical samples.

The National Birdshot Research Network meets two or three times a year, alternating between London, Birmingham and Bristol, and is chaired by Professor Andrew Dick. So far, the network has met five times, and this year (November 2013) has initiated three exciting projects, funded and administered in collaboration with the charity Fight for Sight:

- Establishing the world's first National Birdshot Bio-Resource Centre. This will be housed at the Infectious Diseases Bio-Resource Centre, King's College Hospital, London. This initiative is being trialled in three centres
- Establishing a National Birdshot Uveitis Registry database. This is being developed at Birmingham University, Queen Elizabeth Hospital and Birmingham and Midland Eye Centre and will be trialled initially in Birmingham
- A pilot study of the effect of 670 nm light exposure on retinal function and structure in birdshot chorioretinopathy. This is being trialled by Carlos Pavesio in his Moorfields Eye Hospital uveitis clinic

We believe that the National Birdshot Research Network will enable patients and researchers from all over the country to work together more effectively, and that the network's projects will provide a more open access research resource for all those interested in this condition.

For further information or if you would like to be involved, please contact <u>annie@birdshot.org</u>

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National Birdshot Research Network is a partnership between the Birdshot Uveitis Society, the NIHR and leading clinicians in the field of uveitis. It is a unique arrangement designed to ensure appropriate research for the rare disease Birdshot Chorioretinopathy.