

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

National Institute for Health Research



BIRDSHOT UVEITIS RESEARCH PROJECT – 14TH NOVEMBER 2015

Birdshot database recruitment planned for April 2016

The Birdshot Uveitis project comprising research database and collection of samples from people with Birdshot Chorioretinopathy has been a goal for some time. In July, thanks to funding from BUS, a Project Nurse was appointed to continue the work already started by Mr Alastair Denniston at UHB.

Most of the work has been unravelling the governance issues associated with the possible different approaches to the project which aims to recruit patients at a number of centres around the country. The first centres to be set up will be:

First Regional Birdshot Centres:

Bristol Eye Hospital (University Hospital Bristol BHS FT) (Prof A. Dick)

Birmingham and Midland Eye Centre (Sandwell and West Birmingham NHS FT) (Prof P.I. Murray) Guy's and St Thomas' NHS FT (Prof M. Stanford)

Moorfields NHS FT (Miss N. Okhravi)

University Hospital
Birmingham NHS FT (Mr. A.
Denniston)

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Human Biomaterials Resource Centre to Biobank for Birdshot

The Human Biomaterials Resource Centre (Birmingham) is part of Birmingham University and is based on the University Hospital Birmingham cam-pus. The centre will receive collected specimens and process, track and store them for use in future re-search

Any researcher wanting to use the specimens will have to complete an application form which will be considered by an advisory committee. When any applications to use the Birdshot samples are being considered a representative (or two) from the Birdshot community can be co-opted onto the commit-tee to consider the application. The birdshot samples will constitute a rare disease collection and as such can only be used for research into Birdshot Uveitis.

Applications are, therefore, likely to come from the small team of Birdshot Researchers

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The Birdshot project will invite people with Birdshot chorioretinopathy and other forms of severe uveitis to participate in a Birdshot database and a sampling project.

The database and samples will be linked by code so that all samples removed will have data attached and available for use by researchers. The data collected may equally be used alone.

Database

- UHB Governance Dec 2015
- Data Collection tool Dec 2015
- Protocol, PIS, ICF Jan 2016
- Ethics Submission Jan 2016
- Database training Mar 2016
- Ethics Meeting Mar 2016
- Monitoring and Audit Ongoing
- Start Recruitment Apr 2016
- Online resources Jun 2016

Human Biomaterials Re-source Centre (Birmingham) (HBRC)

- Site Agreements Feb 2016
- Collection Kits Feb 2016
- Advertise
- Recruitment Mar 2016
- Start recruitment Apr 2016

Birdshot Uveitis Society: email info@birdshot.org.uk