

Birdshot Research News - December 2013

BUS is delighted to announce that three exciting research projects are about to commence:

- 1) the development of a National Birdshot Bio-Resource Centre (biobank)
- 2) the development of a National Birdshot Uveitis Registry database
- 3) a novel treatment for birdshot to be trialled at Moorfields Eye Hospital: Can exposure to 670nm infra-red light improve retinal function and structure?

National Birdshot Uveitis Bio-Resource Centre project

This research proposal will establish the world's first birdshot uveitis bio-resource centre, or biobank.

Biobanks collect and store donations of anonymised patient samples of blood, urine and other tissues. Approved researchers can then use these materials, feeding back their research data to the biobank. This adds to the original information held about the samples, which increases their usefulness to future researchers.

Rather than set up an independent birdshot bio-resource centre, it makes economic sense to use an existing one. The established Infectious Diseases Bio-Resource Centre at King's College Hospital, London, has expanded to include collections of samples from patients with inflammatory conditions. This means that the Birmingham-based researchers' proposal to set up the birdshot bio-resource within the bio-resource at King's College Hospital fits in well with King's existing work.

The project will start by recruiting a small number of birdshot patients from St Thomas' Hospital, London, Moorfields Eye Hospital, London, and the Birmingham and Midlands Eye Centre, to donate samples to the bio-resource centre.

Clinical data from the National Birdshot Uveitis Registry (see below) would accompany the bio-resource samples. The combined assets of the National Birdshot Uveitis Registry and the National Birdshot Bio-Resource Centre will enable a great variety of statistically-valid and useful studies to be performed on large numbers of birdshot patient samples. It is hoped that the birdshot bio-resource will eventually provide the opportunity for all UK birdshotters to contribute to research by donating their samples. Our involvement will provide the keys to help researchers start to unlock some of the mysteries of birdshot and to improve its treatment.

Developing a UK-wide National Birdshot Uveitis Registry

To be statistically significant, medical studies need to be done on large numbers of patients. Because birdshot is a rare disease, it has been difficult up to now to recruit enough patients to do useful research. Although large studies of up to 80 birdshot patients have been carried out in several European centres, similar scale studies have not been conducted in the UK, principally because birdshot patient information is not held in one place. Creating a national registry database of UK birdshot patients would provide a resource of information on birdshot which would have many potential uses.

The proposed National Birdshot Uveitis Registry (NBUR) will collect and hold clinical data on birdshot patients centrally, including test results such as angiograms and OCT scan images. From the initial pilot study involving data from a few patients at University Hospitals Birmingham and the Birmingham and Midland Eye Centre, the eventual aim is for all UK birdshot patients to be invited to register with the NBUR.

The first step in the proposed study will be to develop a patient details database at University Hospitals Birmingham, test it and perform some data analysis. The database will be tried out with data from a small number of Birmingham birdshot patients, modified as necessary, and then piloted at National Birdshot Research Network partner sites in the UK.

One use of the registry data will be to accompany the samples sent to the UK birdshot research bio-resource centre (see above). Other proposed uses for the data include identifying patients suitable for clinical trials, collecting drug safety data, especially for newer treatments, and eventually being able to identify 'best practice' and promote better care by enabling treatment centres to compare the progress of their patients within the context of a national picture.

University Hospitals Birmingham already develops and operates national databases through their established Rare Disease Service, so this experience will be invaluable in setting up the National Birdshot Uveitis Registry.

Novel treatment for birdshot to be trialled at Moorfields:

Can exposure to 670nm infra-red light improve retinal function and structure?

BUS is delighted to announce forthcoming research into a novel treatment for birdshot which is being trialled at Moorfields Eye Hospital. The Director of Medical Retina and Uveitis, consultant Carlos Pavesio, the lead researcher, will be investigating whether using a particular wavelength of light will reduce inflammation in the eye and improve retinal function and structure in birdshot uveitis.

The initial study will involve only 10 to 12 patients from Carlos Pavesio's clinic. His research team aims to study the effects of 670nm infra-red light treatment on patients with 'grumbling' birdshot disease, with their signs of inflammation continuing to be treated with medication throughout the trial.

Targeted treatment

Birdshot is an eye disease with no known involvement of other parts of the body. Because of this, effective treatment directed just to the eyes would be a big step forward. 670nm infra-red is a part of the natural light spectrum. The energy levels and wavelength of the 670nm light used in the study are lower than those of indirect light on a spring morning. This light wavelength is also emitted from conventional light bulbs, but it is absent from strip lights and also absent from all the new low energy eco-friendly domestic light bulbs.

Study patients will receive 670nm light treatment from a specially-designed light. Treatments will be given on weekdays for two weeks for a total of ten treatments. Each light treatment lasts one minute. Only one eye per patient will be treated but the other eye will be observed as a 'control' for comparison.

In active birdshot uveitis, there is a measurable delay in response to the 30Hz ERG flicker test stimulus, so before the first light treatment for each patient in the trial, a baseline comprehensive ERG will be done. During the trial, patients will be given further ERGs before and after each light treatment, and these ERGs will be performed with a hand-held ERG device (RETeval) where the electrodes are placed on the skin under the eye. These pre- and post-treatment ERGs will check if the light treatment has improved the ERG response.

It will take no more than two minutes to do the study ERG tests, and the eyes do not have to be dilated. The ERG results will be immediately available, so the clinicians will quickly know if there are any improvements in the eyes.

Depending on the results of this small trial, the researchers aim to run a larger study over a longer period of time to assess the usefulness of this special light therapy as a treatment option for birdshot.

[**See the YouTube video of the RETeval ERG device by clicking this link**](#)

This project combines the skills of the medical retina department at Moorfields Eye Hospital with the experience of using this therapy in the laboratory environment of the Institute of Ophthalmology. Both are world leaders in addressing ophthalmic problems.

Funding

These three projects are coming to fruition thanks to the imagination, ingenuity and resourcefulness of clinicians and research scientists who are involved in the National Birdshot Research Network and thanks to the collaboration with Fight for Sight who are providing the administration and partial funding for the projects.

The Bio-Resource Centre project and the novel treatment for birdshot uveitis are being jointly funded by BUS and [Fight for Sight](#), the main UK charity dedicated to funding eye research to prevent sight loss and treat eye disease. Half of the cost of each of these two projects has been raised by birdshotters who took part in the 2012 Carrots Nightwalk, a six and 15 mile charity walk, with matched funding via a Fight for Sight Small Grant Award of £15,000 for each project.

The development cost of the National Birdshot Uveitis Registry is being funded by BUS with money our supporters have donated over the last year, plus donations from the BUS 2013 Shoot, which is our major fundraiser. This project will be administered by Fight for Sight.

1st December 2013