

## A brief history of the Birdshot Uveitis Society

The Birdshot Uveitis Society (BUS) was formed as a patient support group in 2009. It is run by volunteer members, for members, and became a registered charity in 2012.

One of the two founders, **Annie Folkard**, remains the main point of contact for BUS.



With help from some of the volunteers, Annie undertakes the tasks required to keep the charity and support group running efficiently. Annie has Birdshot.

A successful business man, **John Hall**, who is a director of BUS, provides the Charity with his vast experience and extensive knowledge. John has Birdshot.



The Charity's treasurer is **Peter Edney**, a practicing accountant who helped us achieve charitable status. Peter's wife, Janie has Birdshot.

David Bethell designed our logo and creates our posters and leaflets. David has Birdshot.

Joanne Hawkins administers Gift Aid to increase our income. Joanne has Birdshot.

Barrie Standish is one of our Facebook administrators. Barrie has Birdshot.

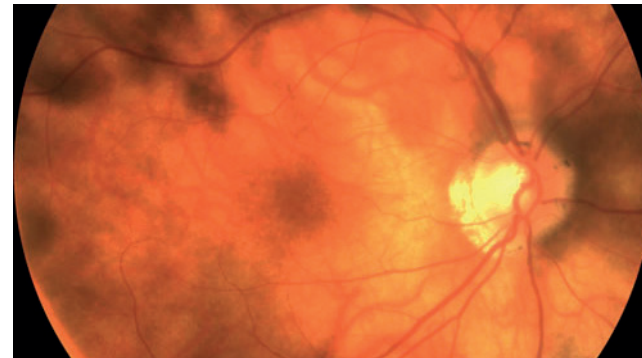
### Our aims are...

- To give support when Birdshot is diagnosed.
- To provide current information about the condition and treatment options.
- To build better services and pathways to the specialist treatment required.
- To raise the profile of Birdshot.
- To help prevent avoidable sight loss.
- To encourage research into Birdshot.
- To promote international links with Birdshot researchers in other countries.
- To fundraise in order to achieve our goals.

### Our achievements...

- Established a National Birdshot Research Network of clinicians and medical scientists.
- Set up a website containing fact sheets to download, helping patients understand Birdshot, its medications, monitoring and tests.

- Published a Birdshot Survival Guide of tips and facts to help with the Birdshot journey.
- Published a video and audio presentation and personal Birdshot stories.
- Organised regular 'Birdshot Days' to enable patients, doctors and medical scientists to meet and exchange information.



Eye with Birdshot spots.

- Set up and maintained an active International Facebook support group.
- Organised local group meetings for Birdshot patients.
- Raised the profile of Birdshot nationally and internationally, by co-authoring published papers and speaking at meetings.
- Contributed to National Institute for Health and Care Excellence (NICE) assessments for new treatments approved in England and Wales.

- Supported the development of a UK database and biobank to provide resources to help researchers investigate Birdshot.
- Funded a UK wide Birdshot surveillance study to record the numbers of newly diagnosed patients.
- Worked in partnership with Fight for Sight to provide co-funding for research projects, focusing on improving Birdshot diagnosis, treatment and understanding.

### Why we need your help...

Your donations will enable research into preventing needless sight loss and finding better ways of treating this blinding eye condition.

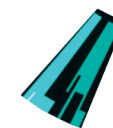
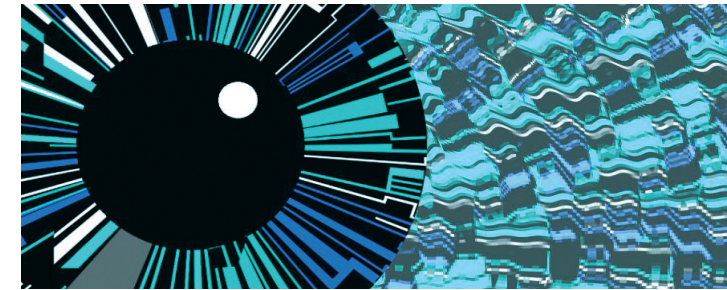
You can make your donation online at [www.birdshot.org.uk](http://www.birdshot.org.uk) or by cheque, payable to Birdshot Uveitis Society.

### Please contact us...

If you have been diagnosed with Birdshot, we want to hear from you.

If you are a healthcare professional who wants to learn more about Birdshot, or if you are already an expert in Birdshot and can help BUS in any way, we would welcome your involvement.

[www.birdshot.org.uk](http://www.birdshot.org.uk)



### **BIRDSHOT UVEITIS SOCIETY**

A support group for people with the rare, hard to treat, autoimmune, posterior uveitis called Birdshot Chorioretinopathy

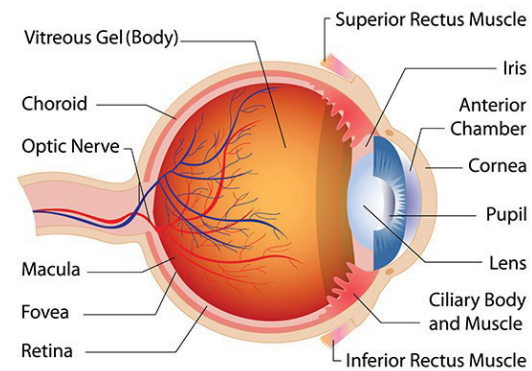
... you are not alone...



## What is Birdshot?

Birdshot Chorioretinopathy is a relatively new eye condition, first described in 1949. It is a rare, potentially sight-threatening chronic posterior uveitis which usually affects both eyes.

Uveitis is inflammation of the uvea, the part of the eye composed of the iris, choroid and the ciliary body. The uvea provides most of the blood supply to the retina.



## Birdshot Symptoms...

Usually, the first symptoms are 'floaters' and blurred vision caused by vitritis; which is inflammatory cells in the vitreous (the jelly-like substance in the back of the eye). This leads to a gradual, painless difficulty in seeing with one or both eyes.

As Birdshot progresses, an ophthalmologist may see orange or cream coloured oval spots on the retina. The pattern of the spots resemble those seen when pellets are fired from a shotgun, hence the name 'Birdshot'.

Because it is such a rare disease, it is often misdiagnosed or sometimes missed completely in the early stages, particularly as the Birdshot spots are not clearly visible at first.

## Other symptoms may include...

- Night blindness or difficulty seeing in dim light.
- Problems with colour vision.
- Sensitivity to bright lights or glare.
- Seeing flickering or flashing lights.
- Distorted, fluctuating or shimmering vision.
- Decreased ability to judge depth.
- Decreased peripheral (side) vision.
- 'Ceiling fan' effect: seeing an image of a whirling ceiling fan when the eyes are closed.

## What causes Birdshot?

It is not known what causes Birdshot. It is believed to be an autoimmune disease which occurs when the body's tissues are attacked by its own immune system.

Almost everyone diagnosed, has inherited an antigen called HLA-A29. It is not yet known why some people who carry HLA-A29 develop Birdshot and others don't.

## What is the course of Birdshot?

Birdshot is a potentially sight-threatening disease. The most concerning issues are that if it is left untreated, or if there are repeated flare-ups, this can lead to macular oedema - a swelling caused by fluid collecting under the macular layer of the eye - which can lead to visual loss.



## Is there a cure for Birdshot?

Currently, there is no known cure. The goal of treatment is the remission of symptoms.

Each person's Birdshot is different: it does not follow a set pattern and it responds differently to the various medication regimes tried.

Most research concentrates on investigating more effective medications that have fewer side-effects than those currently used.

However, there is also research going on to investigate the genetic links and triggers for Birdshot.

## Birdshot treatment...

This is based on a combination of corticosteroids to reduce eye inflammation plus immunosuppressants, or more recently, biologics to control the over active immune system.

These treatments are usually taken by mouth, but some are injected or implanted into the back of the eye or injected under the skin. See our website for information on treatments.

### Contact BUS on:

Birdshot Uveitis Society  
PO Box 64996, London, SW20 2BL

**T: 0845 605 1195**

**info@birdshot.org.uk**

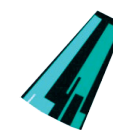
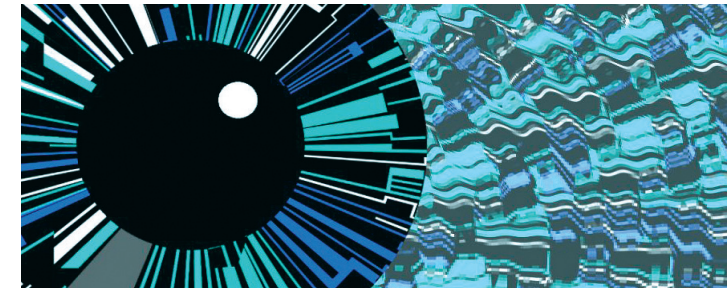
**www.birdshot.org.uk**

**Facebook support group**  
**Birdshot Uveitis Society (International):**  
<https://facebook.com/groups/Birdshot/>

**Twitter:**  
<https://twitter.com/birdshotcharity>

Registered Charity Number: 1145349  
Registered in England & Wales.  
Company Number: 7716343

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