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## ANNIE FOLKARD

**Firstname:** Annie

**Surname:** Folkard

**Eye Hospital:** Moorfields Eye Hospital

**Country:** United Kingdom

**Function:** Co-founder of Birdshot Uveitis Society



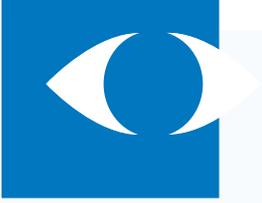
### The power of the patient voice

1. Building a Birdshot Community
2. Working with professionals, researchers and consultants form the main uveitis centres within the UK
3. Fundraising to enable £250,000 worth of research to take place
4. Holding Birdshot Days and encouraging collaborative partnerships
5. Enabling patients to get the most out of their treatment

### Summary

The presentation will describe how, over the last 10 years, the Birdshot community was developed by a small group of Birdshot patients with help from Moorfields Eye Hospital. Now with over 800 members from across the world, we have started to work with researchers and professionals and launched a birdshot biobank and database in 6 main centres in the UK. We have part funded a project manager to help with the rolling out of this resource to the centres across the country, established a collaborative community where patients and professionals can work together and share information.

Key partners in this initiative include Prof. Andrew Dick, Prof. Miles Stanford, Prof Alastair Denniston, Prof Philip Murray, Carlos Pavesio, Richard Lee and Narciss Okhravi, as well as the charity Fight for Sight.



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## **Descriptive CV**

In 2010, I help establish a patient support group, called the Birdshot Uveitis Society (BUS), run for people with a potentially blinding rare condition known as Birdshot. This is a condition which I suffer from, and about which little is known. In 2012 BUS became a registered charity and over the years, have been successful in raising Birdshot's profile. Our annual income, in excess of £50,000, is used to fund research and run vibrant Birdshot days where patients and professionals, collaborate and learn from each other. BUS have also set up a National Birdshot Research Network, involving patients, and specialists in the field of uveitis. We have financially supported numerous small birdshot research projects in partnership with Fight for Sight.