

Bringing together patients and specialists:

The first ever UK Birdshot Patient Day: Can it shape future care and research?

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Introduction & Purpose

A group of health professionals and members of a patient support group, alongside a team of health research managers, public engagement officers, event organizers and audio-visual specialists, have set up the first UK Patient Day for Birdshot Chorioretinopathy, a rare and sight-threatening form of posterior uveitis.

- The Patient Day's objectives were to:**
1. Reduce the sense of isolation of patients with this rare disease,
 2. Raise the profile of the condition,
 3. Allow a two-way exchange of information between patients and professionals,
 4. Help to obtain better visual outcome for patients,
 5. Provide a base for research

Birdshot Chorioretinopathy is a rare and poorly understood form of bilateral posterior uveitis, which in the absence of prompt diagnosis and adequate immuno-suppression, results in irreversible loss of visual function. The disease is chronic, progressive and lasts the duration of a patient's life. It affects patients of all ages with dire effects on quality of life. There is no known cure.

Methods

The instigating collaboration

Annie & Rea patient experts and founders of the Birdshot Uveitis Society & Miss Narciss Okhravi, Consultant Ophthalmologist

Recruiting the team

Nurses
Consultants
Trainee eye-doctors
Fundraisers
Medical students
Optometrists
Artists
Exhibitors
Audiovisual experts

Institutional support

A Beacon Bursary grant from the Public Engagement Unit of University College London
The NIHR/Biomedical Research Centre at Moorfields Eye Hospital
Moorfields Eye Hospital NHS Foundation Trust
The Moorfields Eye Hospital R&D Department

Publicity & Advertising

Through a poster designed by a Birdshot patient and sent to the majority of the Eye departments in the UK and a number of published articles
In a poster prepared by BUS and presented at two ophthalmic conferences and the VISION2020 Conference in June 2010

Consultant Uveitis Specialists

Carlos Pavesio
Mark Westcott
Narciss Okhravi
Christine Fardeau
Guy's and St Thomas NHS Foundation Trust
Miles Stanford

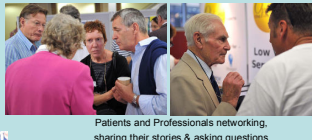
Guest Speakers

Mike Brace Chief Executive
Pill Hibbert Chief Executive
Melissa Hillier Assistant Director
Genentech Alliance UK
UITG

Result: The Birdshot Patient Day

126 attendees

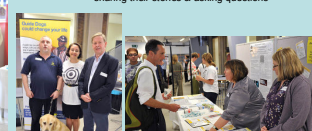
- 50 Patients & 26 supporters travelling from as far away as Northern Ireland and Scotland
- 50 Health care professionals attending from across the UK and abroad



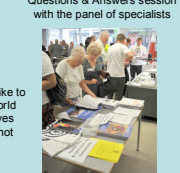
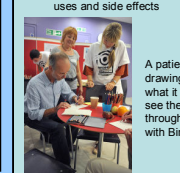
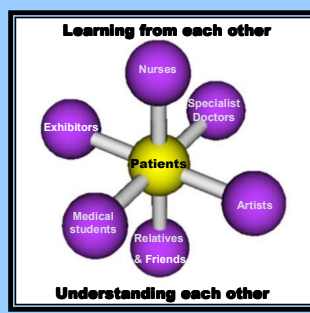
Patients and Professionals networking, sharing their stories & asking questions



Patients were interviewed about their experiences. Footage was used in a DVD produced for publicity and education



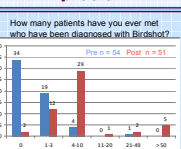
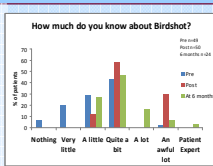
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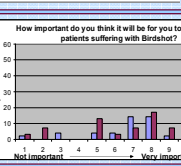
Evaluation of the Day

Patients and supporters

The level of knowledge of patients and their supporters improved by the end of the day. Patient knowledge at 6 months was still statistically significantly greater than prior to attending the meeting ($p=0.015$)



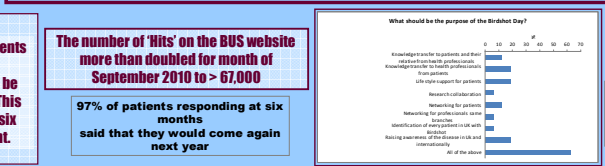
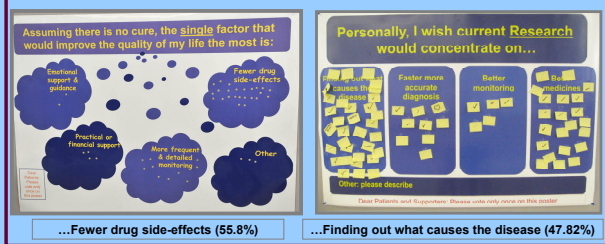
Many had never before met another individual with Birdshot
In the 6 months following the BCR Day, 47% of patients had been in touch with another individual with BCR



The vast majority of patients thought it was very important to be able to meet fellow sufferers. This belief was firmly held six months after the event.

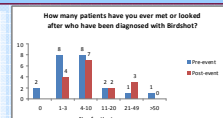
Structured anonymised questionnaires and formal interactive evaluation techniques were used to fully evaluate the success and short and long term (6 months) impact of the day on both patients and professionals.

The patients' answers were not always what the professionals would have guessed they would be



Health Professionals

The majority of health care professionals had only ever met or cared for less than 10 patients



In the 6 months following the event, 52% of health professionals had been in touch with at least one other newly acquainted BCR colleague.
The majority of participating health professionals thought this networking opportunity had been very valuable.

The level of knowledge of the majority of professionals increased over the period of the Birdshot Patient Day



100% of professionals would recommend this day to other BCR patients
96% of professionals would recommend this day to other health professionals
88% of health professionals would come again next year

Conclusions....

"I no longer feel like a 'forgotten' patient - I feel I now have a future, and more importantly, that anyone related to me has a real chance of being diagnosed and treated effectively, should they get Birdshot. Long live Team Birdshot - you have literally saved my life." Patient with Birdshot & Organising member

"It was really great to see so many people there and so many other people with Birdshot, it certainly makes you feel a lot less alone." Patient with Birdshot
"It was good to meet fellow sufferers and be able to empathise about the side effects of the drugs which puts things into perspective." Patient with Birdshot

"Thank you again for all the hard work you have done to not only educate all of us but to also bring together a community where we can share in each others experiences and not feel alone." Patient with Birdshot
Excellent work. A very impressive seminar. Consultant delegate

"The day was excellent, and I believe has most likely made a positive improvement to the lives of some of the sufferers, and I guess that's the best result you can hope for." Patient with Birdshot
I would say that the conference was an enormous success. The organisation was brilliant. The charity was punching well above its weight. Visual Aid exhibitor

"I can't thank you enough for Saturday; it was so great to finally meet and talk to others who are asking the same questions as me. I can now say that I don't feel so alone and the day has made me feel more positive for the future. Cant wait for next year!!!!" Patient with Birdshot

"Birdshot Day was highly extraordinary and an opportunity for us as Healthcare professionals to reflect and gather our thoughts pertaining to our patients." Specialist Nurse
Really great day - lots of help, thanks so much to all involved. Anonymous

I can't begin to tell you how much I gained from attending the birdshot day - just from a research management viewpoint! I think we ought to set up a series of meetings like this involving patients, patient groups, clinicians and researchers. Research manager

"It struck me how few no-shows there were for such an event - I think you can put that down to the great organisation and the enthusiasm for the event that you'd capitalised on. Well done!" Public Engagement Officer
What a great day it was. Well done and thank you for all the hard work that you must have put into the Birdshot Day. It was very impressive and I certainly learnt a fair deal. Anonymous health professional