

Birdshot Patient Day Report

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Objective:

To make visual representations of birdshot chorioretinopathy ('Birdshot') using drawing as tool for communication.

Activity:

All people attending the Birdshot Uveitis Day at UCL on 11th September 2010 were encouraged to make a drawing to express their understanding of the experience, diagnosis and disease process of Birdshot. It was anticipated that different groups would produce diverse images. Colour was provided, but not expressly encouraged, as the disease can affect colour perception. A5 paper was provided as it was felt larger pieces could be rather intimidating, paper size also corresponding to the more intimate hand size, simultaneously allowing space for both drawing and any written explanation.

Two medical students (see acknowledgements) together with myself as lead artist provided assistance for participants as well as organising and recording drawings and equipment.

Findings:

Initially attendees needed a lot of support and encouragement from the art team to have the confidence to take part in the activity. Patients were the most active in taking part, and all those that used the activity added words within their drawings. They were much more confident to make images that reflected the actual experience of Birdshot, producing abstract images corresponding to visual disturbances and diminishing visual acuity. Patients were especially interested in explaining 'Vibrating Vision' – something that one of the Consultant Ophthalmologists particularly raised during the first set of lectures. Many were keen to express the diverse symptoms of the disease (*images PD 001.1. 3, PD 001.1. 3 PD 001.1. 3*), and this is particularly noticeable in the range and styles of the images produced.

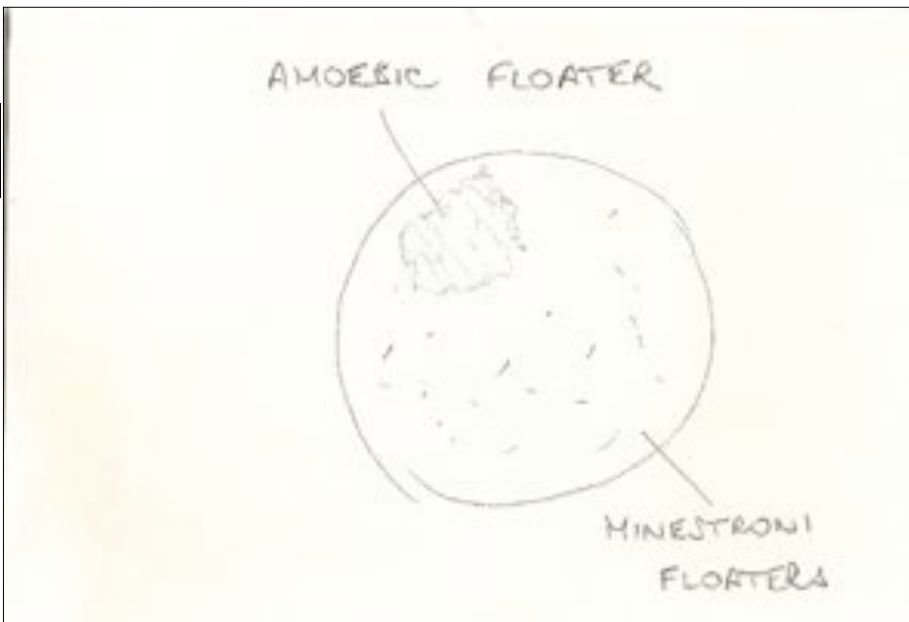


Image PD 001.1.3. First drawing of three showing symptoms across eyesight

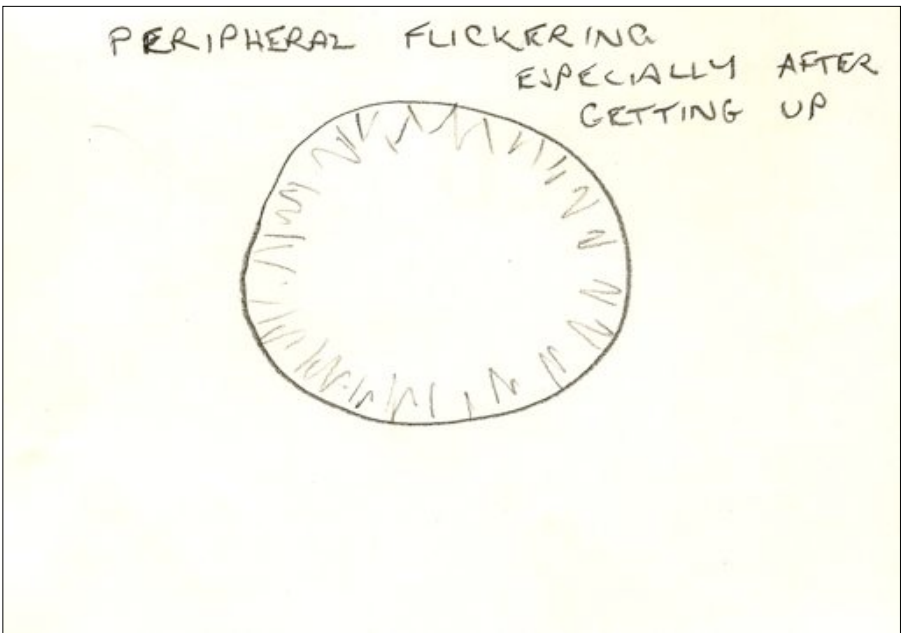


Image PD 001.2.3. Second drawing of three showing symptoms giving explanation of time as well as area of disturbance

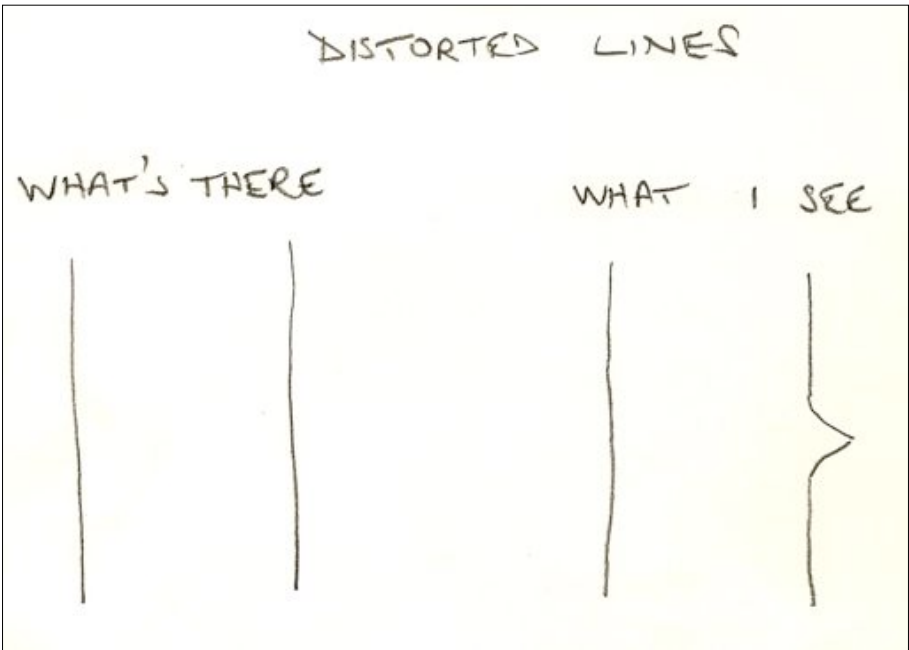


Image PD 001.3.3. Third drawing of three explaining changes in vision in sight in both right and left eyes.

Very few patients acknowledged any art training or art interest, coming to the drawing activity as an additional way of expressing and explaining their experiences. For the most part the drawings had very strong expressive and compositional structure. Although the activity was very much not designed as an Art Therapy activity, the patients seemed to welcome the opportunity to be able to clarify their experiences in visual form. Each person came at different points in their disease, from pre-formal diagnosis, to those having undergone many different forms of treatment over a number of years, and those who had very little residual sight. Different aspects of the disease were illustrated showing a range of symptoms which each patient felt caused them significant problems although some patients used more than one page to describe two symptoms most limited themselves to expressing the one uppermost concern for them. (As in image 004.1.2 which combines images made on two sheets of paper)



Image PD 004.1.2 showing elements of 'vibrating vision' within a limited palette range – this image a combination of sketch over two pieces of paper, the only example of work breaking out of the A5 size convention

Some patients were able to differentiate the dynamic changes in each eye and used drawings to begin to quantify the effect of visual disturbances as well as changes in colour or night vision.

(Images PD 001.3.3 PD 002.1.1)

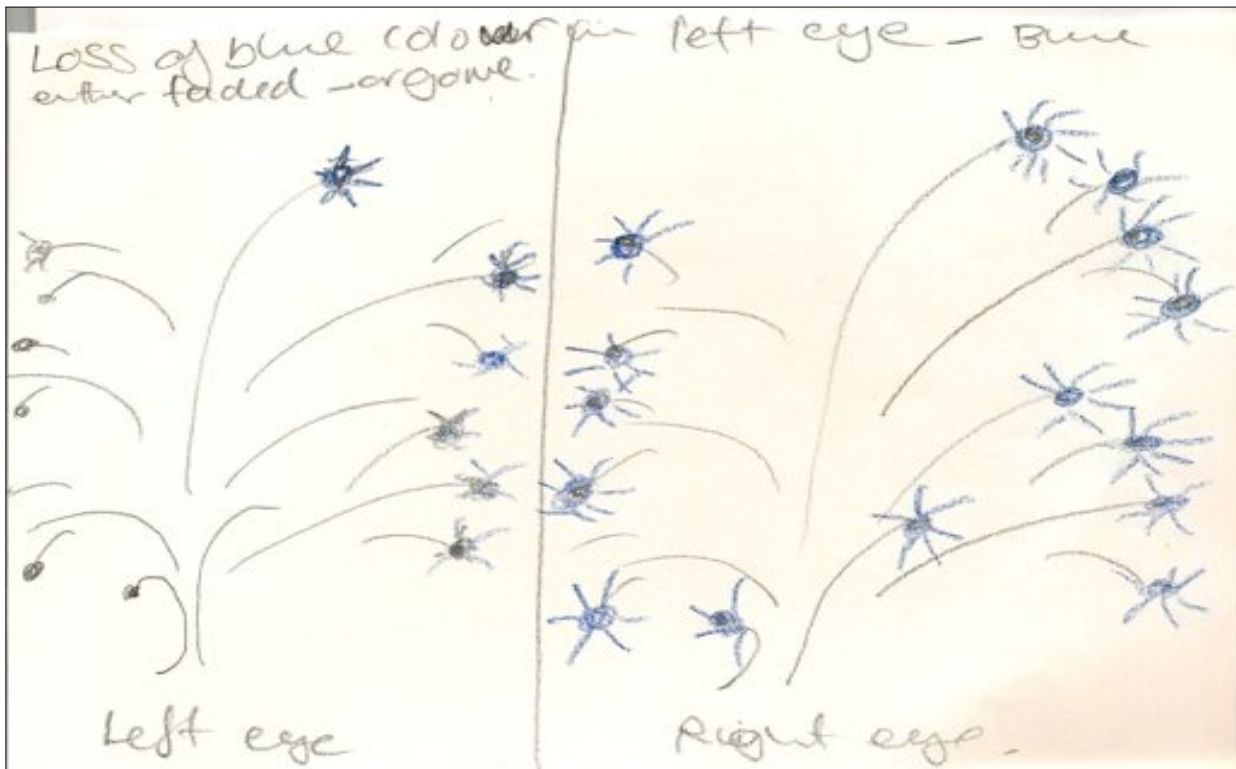


Image PD 002.1.1. Explanation of changes in colour vision in specific areas of left and right eye, together with flashing lights

The few supporters (relatives, partners or friends) who made drawings showed some understanding of the patients restricted visual field, one supporter making an expressive abstract piece showing a detailed understanding of the visual perception of the patient she was with,(PS 002.1.1) whilst another made a drawing that appeared to recall an incident that marked a significant moment in developing their understanding of the problems facing someone with Birdshot, this person made a more 'realistic' image with a detailed explanation of the occurrence.(PS 001.1)

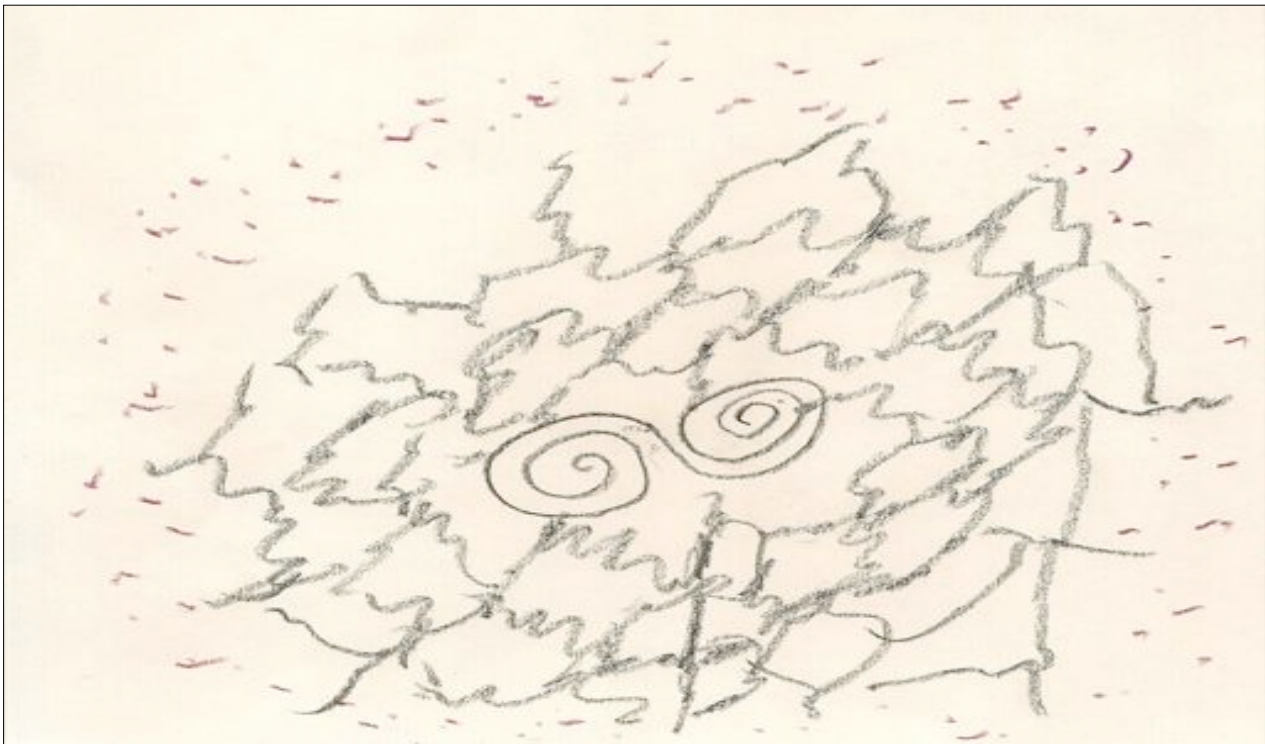


Image PS 002.1.1 Image of supporter's perceptions of visual disturbance using colour and textured marks to define areas and explain distortions

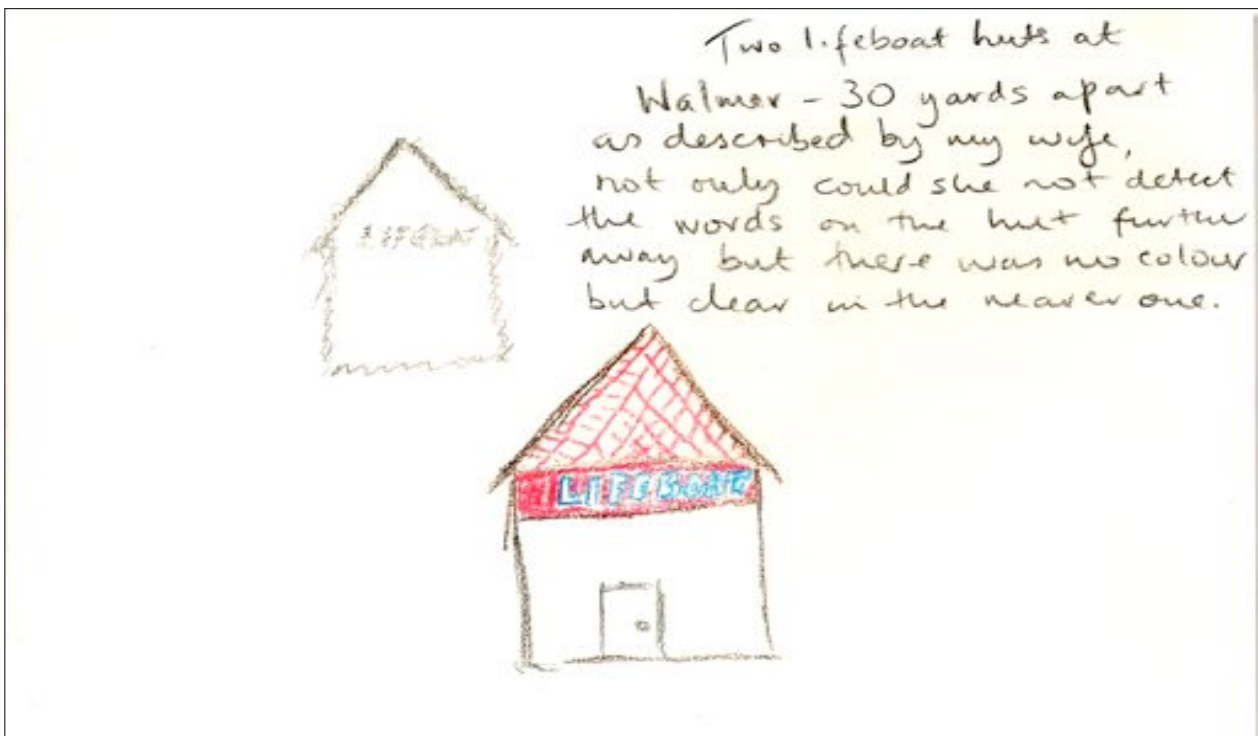


Image PS 001.1.1 Clear description in text and image of a significant event as an example of loss of visual acuity and colour

Medical students approached the activity with varying degrees of enthusiasm, and generally made images that were more literal and diagrammatic, linking the physical structure of the eye with an interpretation of one of the symptoms overlaid – for example a ceiling fan image within a bird body the literal interpretation of one of the visual symptoms within the designation of the disease.(Image *MS 001.1.1*) It could be that the students were aspiring to produce a piece of ‘finished’ art work which would be a public explanation of a totality of knowledge rather than a more personal reaction to the information that they had gathered from the mornings’ lectures and the many discussions they had had with patients and their supporters.



Detail from image MS 001.1.1 Medical student's work containing combined references to disease symptoms and elements of Birdshot name

However one student's interpretation of a visual disturbance coincidentally depicted by a patient had some strong similarities – both were abstract representations of flares experienced at the outside edges of the visual field, the patient's works had greater strength of line and was much simpler, the student, who had some art training had similar structure, but had more Fine Art drawing motifs – variety of tone and mark – having a very similar compositional value, expressing the linearity of the

optical disorder. This more abstract work would seem to imply a more empathetic understanding of the visual disturbance experienced by patients, whilst other medical students' work appeared to have a more embellished way of explaining or advertising the disease.

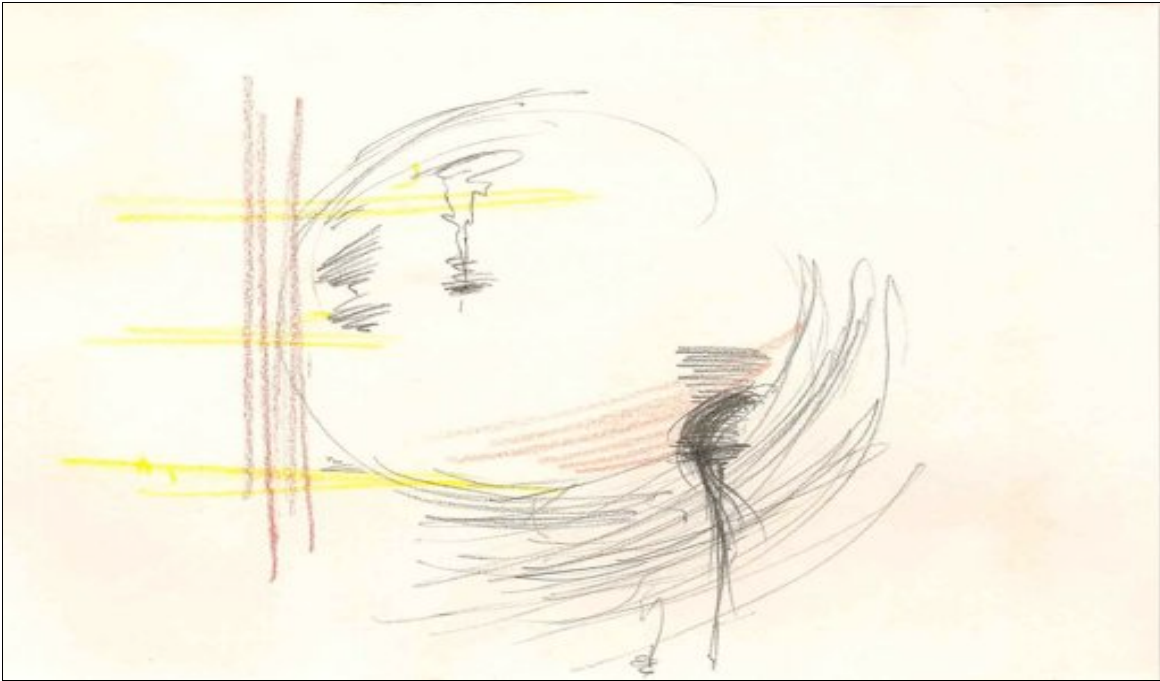


Image MS 004.1.1 Medical student's work showing flashes at periphery of vision

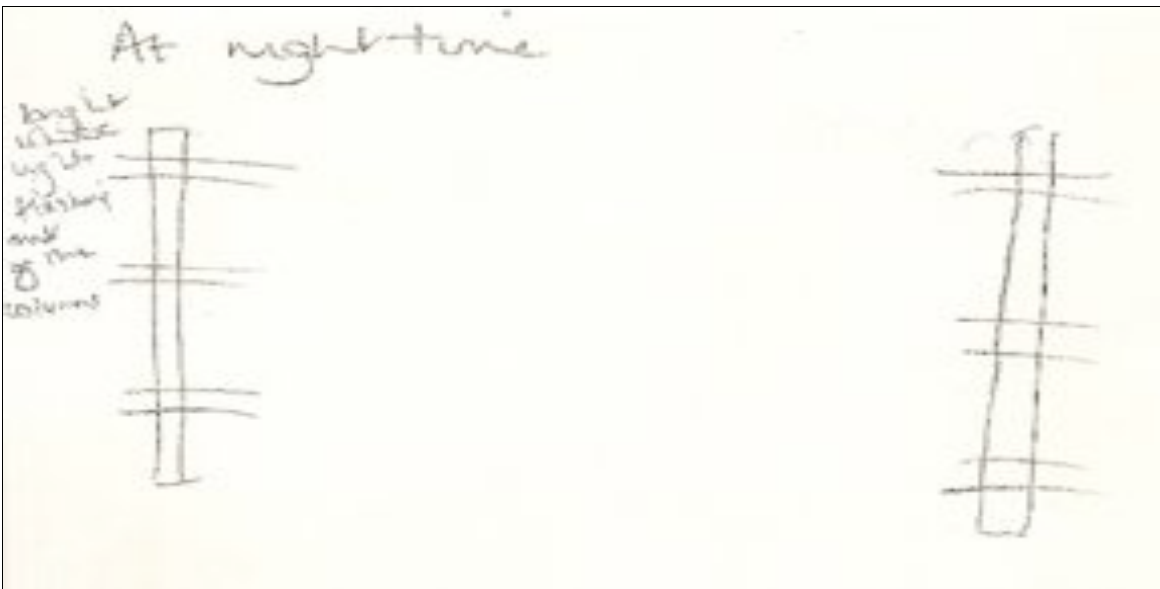


Image PD 003.1.2 First of two drawings made by patient explaining flashes at periphery of vision

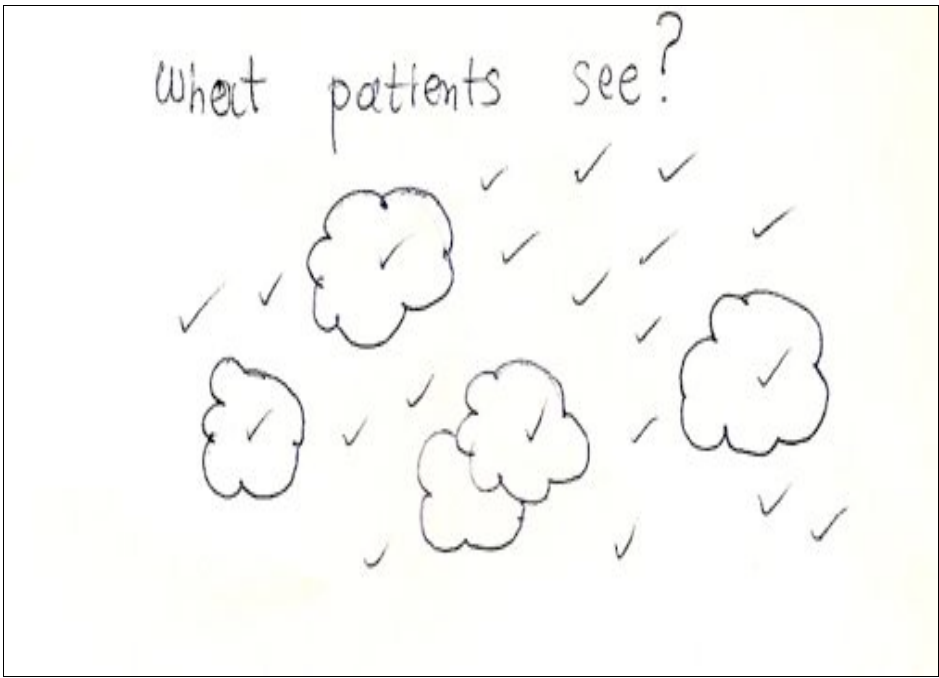
The work of another art trained medical student arose from images from one of the first lectures – a

slide of damaged choroid tissue – which examined both the physical effect of oedema on the tissue structures with the patches of damage linked to some of the symptoms experienced by the patient. (*Image MS 005.1.1*) This ambitious attempt at simultaneously recording the temporal physical changes within the body of the eye whilst acknowledging the symptoms of areas of lost or damaged vision together with the flashing light experienced by some patients in their peripheral vision.

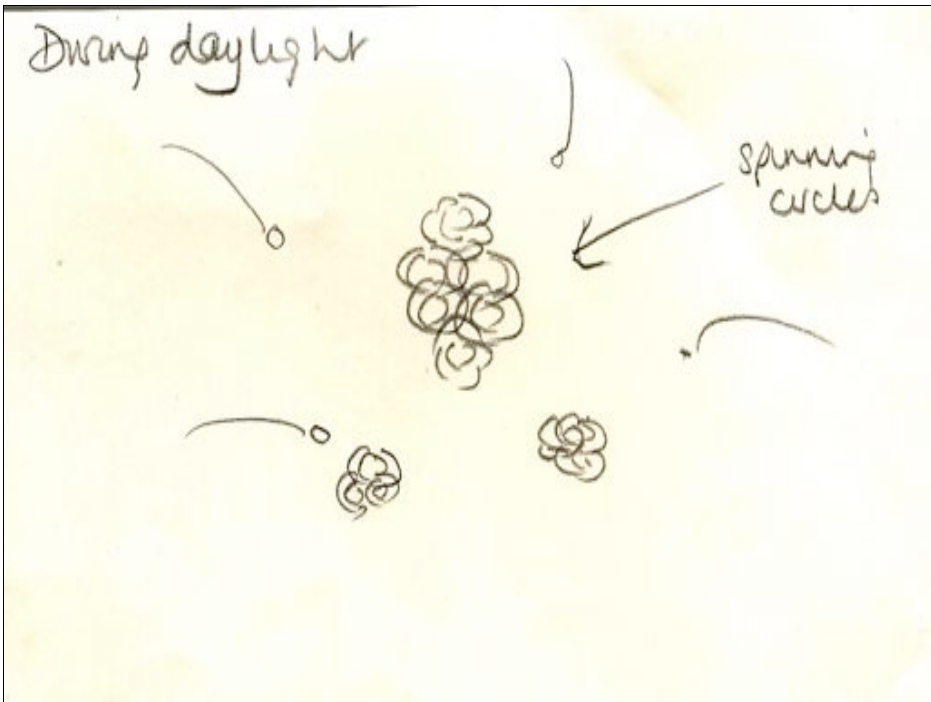


Image MS 005.1.1 Medical student's work showing tissue layers and abstract expression of patient symptoms

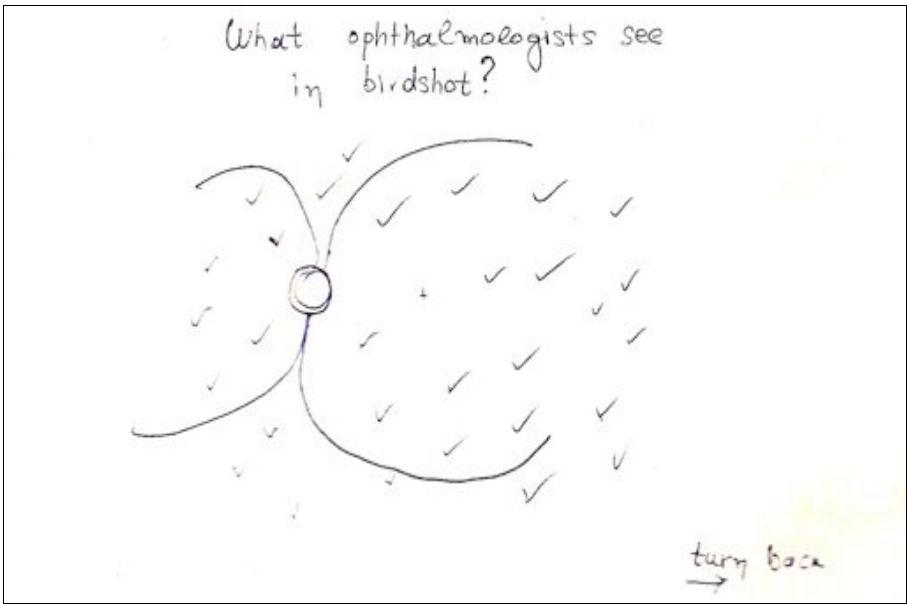
The single work submitted by an ophthalmologist, drawn over two pages would also appear to have strong visual links with the patient's experiences, combining written elements with indications of loss of vision through clouded areas, as seen in the first of the two images below which compare the ophthalmologist's envisioning of a patient's perception with the image produced by a patient showing similar areas of visual disturbance.



*Detail from Image
OP 00.2.2.2
ophthalmologist
identification of
key visual
disorder*

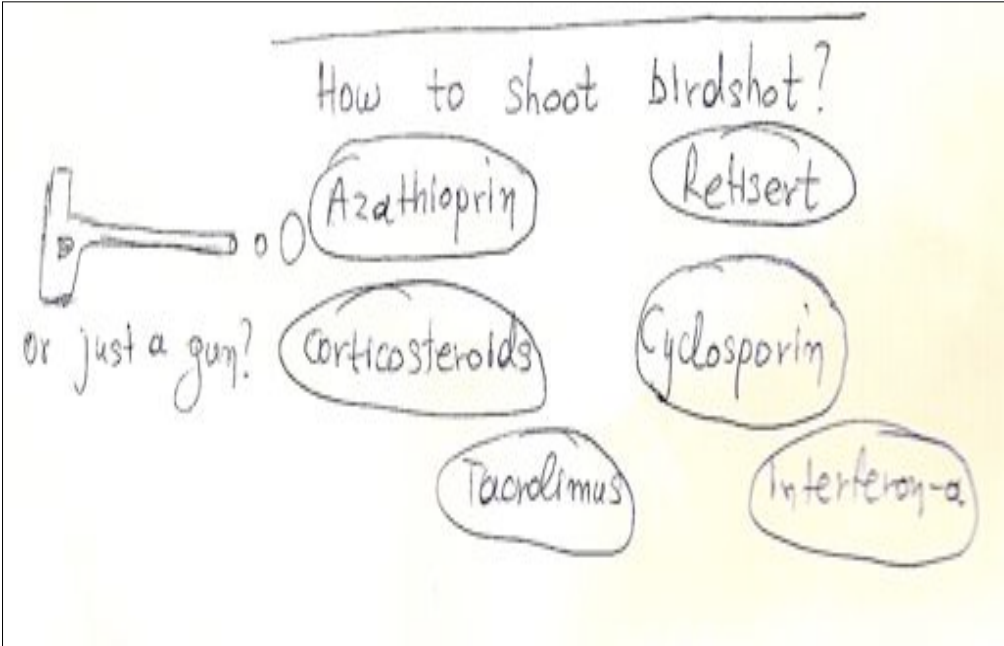


*Image PD
003.2.2 Second
of two patient
drawings
showing patches
of visual
disturbance*



Details from Image OP 00.2.1.2 ophthalmologist drawn recollection of key identifications of Birdshot Uveitis

The image made to show the ophthalmologists viewpoint continues similar symbolic motifs combined with the diagrammatic format of the back of the eye this simple format could be effectively used to show patients and their supporters of how damaged areas are noted – if not in a formal way – which may be related to the areas of visual disturbance or loss. The third section of the ophthalmologists' drawing indicates possible areas of research in terms of different drug treatments, again reflecting issues discussed in the lectures and in patient dialogue before and during the day of the conference.



Detail from Image OP 00.2.2.2 ophthalmologist identification of possible drug treatments

Conclusions

Impact on patients

Patients have remarked on the enormous relief in finding others who suffer the same as them. The sharing of experiences by use of drawing led to an in depth discussion of the symptomatology of the disease (between patients, between patients and supporters, between patients and professionals and between professionals and other professionals). The knowledge that by so doing not only their friends and relatives can better understand, but also the images would be used for teaching the current and future generation of health care professionals (medical, nursing, optometrist) has had a keen impact on the patients who attended the Birdshot Patient Day. Many have talked about 'a sense of hope for the future'. Each knows the importance of raising the awareness of Birdshot Chorioretinopathy as the majority have suffered a delay and doubt over their diagnosis.

Diagnosis

The most difficult aspect of dealing with this disease is its rarity combined with presentation with 'floaters', a common presenting feature in all patients presenting with any eye problems to Nurse practitioners, GPs, Optometrists, and Eye Casualty Departments. Patients often describe very well the symptoms they have had but these are generally considered 'non specific' or 'vague'. It is however the constellation of symptoms that should lead the health care professional to think this is 'not just floaters'.

Signs and Symptoms	All Eyes (n = 160)
Symptoms, n (%)	
Blurry vision	56 (70)
Floaters	53 (66)
Nyctalopia	51 (64)
Abnormal contrast sensitivity	32 (40)
Abnormal color vision	30 (38)
Vibrating vision	17 (22)
Metamorphopsia	15 (19)
Decreased peripheral vision	10 (13)

Baseline symptoms for 80 patients with Birdshot Chorioretinopathy. Table modified from Monnet et al *Am J Ophthalmol* 2006;141:135-142

The use of such images to describe the patients' history is a very powerful way of raising the awareness of Birdshot Chorioretinopathy in the community of health care professionals who are often the first port of call for patients with eye problems.

Monitoring progress

Patients with Birdshot often 'know something is wrong' when not much is visible to the examining ophthalmologist upon slit lamp examination in the clinic. In order to assess the adequacy of immunosuppression treatment (not too much / not too little) often the ophthalmologist has to resort to collecting evidence in the form of visual fields or electrophysiological tests in order to monitor the disease adequately. Images could be used to give an extra indication of disease symptoms and progress. As the disease has to be treated with high doses of steroids, potentially toxic immunosuppressive drugs or with other more experimental drugs such as Interferon A, the images could help support a joint dialogue between patient and doctor in helping to tailor the drugs or other treatment, especially as the medications have quite potent side effects.

Drawing is a simple and cheap method of recording visual symptoms, patients and doctors could

keep a record in image form in order to track the disease progress, loss of peripheral vision or diminution of colour especially within different areas of the colour spectrum could be monitored. One patient brought in such a visual diary that showed the changes in her sight; this small record was a personalised chronicle of the disease and treatment.

Impact on Patients' Support Network

Although many friends and family supporters very highly vocal during the day, only a few made drawings at the workshop. It could be that although they have a great understanding of the impact of the changes in vision in the patient they were reluctant to make a visual representation, feeling that either their input would not be so valuable or direct as that of the patient or the medical professional, or that they were anxious about the drawing task not wanting to expose their concerns or imagined lack of drawing skill. It is possible, however, that they would find in making and comparing images they would also be able to help track or understand the disease process and provide useful additional information for the treatment and care of the patient, as well as additional opportunity for them to refine and develop their understanding of the disease, its process and the impact of different treatment regimes.

Impact on Medical Students

Students found the process an invaluable learning opportunity. Discussing Birdshot with patients, they felt, enhanced their 'active learning'. They were able to discover much about the patients' experiences through the illustrations and the discussions around them as they were being made, and they gained a greater sense of how the disease impacted both the physical and emotional well being of the patient and their families as well as building on their understanding of the morphology and treatment of the disease. The students also noticed that although there were similarities in patient experiences, each visual depiction was patient specific, this highlighted for them the importance of tailored patient care.

The cross disciplinary experience of working alongside an artist provided them with an opportunity to enhance their understanding, whilst at the same time providing patients with support to explore conditions creatively leading to a valuable interchange of knowledge and experiences.

A paper based on the work by the students in collaboration with the artist has been submitted for:

3rd Annual Academic Meeting of the Academy of Medical Educators

“Patient centeredness ... the heart of medical education” Jan 2011

Acknowledgements:

1. All patients and their supporters who attended the Birdshot Patient Day.
2. Medical Students and other health care Professionals who submitted images
3. Robert Wilkinson 2nd year Medical student University College London Medical School, Gower St London, WC1E 6BT.
4. Rebecca Morris 4th year Medical student, University College London Medical School, Gower St London, WC1E 6BT.
5. Annie Folkard and Rea Mattocks, Patient experts and founders of the Birdshot uveitis Society. Birdshot Uveitis Society (<http://birdshot.org.uk/blog/>)
6. Narciss Okhravi. Consultant Surgeon, Uveitis Specialist and Director of Undergraduate Education, Moorfields Eye Hospital NHS Foundation Trust, Honorary Senior Lecturer, UCL Institute of Ophthalmology. London EC1V 2PD
7. All Staff at Moorfields Eye Hospital Research and Development & NIHR-BMRC (BMRC award to Miss Okhravi) and Office of Communications.
8. Hilary Jackson at UCL Public Engagement Unit (Beacon Bursary award to Miss Okhravi)
9. Professor Christopher Dean – Professor of Anatomy UCL, UCL Medical School.
10. The Birdshot Patient Day team.

Additional notes

Images coded PD - patient drawing , MS –medical student OP – other professional
Numbers indicate individual number, number within series and total of images submitted by individual thus MS 001.1.2 is medical student 001, first image in a series of 2