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

Nikolaos Koutroumanos1, Rea Mattocks2, Annie Folkard2, Claudia Wilson-Barrett2, Catey Bunce1, Carlos Pavesio1, Narciss Okhravi1

1Moorfields Eye Hospital, London, United Kingdom; 2Birdshot Uveitis Society, London, United Kingdom

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

Consultant Uveitis Specialists

Consultant Ophthalmologist
• Nurses
• Consultants
• Trainee eye-doctors
• Fundraisers
• Medical students
• Optometrists
• Artists
• Exhibitions
• Audiovisual experts

Patient with Birdshot

The Instigating collaboration

Annie & Rea patient experts and founders of the Birdshot Uveitis Society

Dr Rea Mattocks, Consultant Ophthalmologist

Nurse with Birdshot

The Recruiting the team

Moorfield’s Eye Hospital R&D Department

Enrolment of participants: Moorfields Eye Hospital Research and Development, in particular Peng Khaw, Sue Lydeard, Isabel Moldon, Catey Bunce and Rebecca Peasgood.

Guest Speakers

Consultant Uveitis Specialists

Birdshot Uveitis Society, London, United Kingdom

Consultant Uveitis Specialists

Patient with Birdshot & Organising member

The Institute of Ophthalmology, London, United Kingdom

What will you be able to do as a result of attending this meeting?

0 10 20 30 40 50 60 Knowledge transfer to patients and their relatives from health professionals Knowledge transfer to other patients and supporters Other

Result: The Birdshot Patient Day

Result: The Birdshot Patient Day

Publicity & Advertising

On the day, a special edition of the UK’s first patient newsletter was published, with the main aim to reach and inform the patients.

Evaluation of the Day

Structured anonymous 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.

Guest Speakers

Methods

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods

Consultant Uveitis Specialists

Methods