

# Patient and Public Involvement

at the NIHR Biomedical Research Centre at  
Moorfields Eye Hospital NHS Foundation Trust  
and UCL Institute of Ophthalmology



## 2015 Activities

**The NIHR Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology (NIHR Moorfields BRC) seeks ways to support the involvement of patients and the public in influencing the vision research that is conducted on our site to support our work in developing 'A Vision for Vision'.**



## **A Vision for Vision**

**We need the views, experiences and insights of patients, family members and friends to ensure that research meets the needs of people affected by eye conditions.**

**Examples of how we worked with patients and the public to this end in 2015 are given here.**

# About the NIHR Moorfields BRC

The NIHR Moorfields BRC is a partnership between Moorfields Eye Hospital NHS Foundation Trust and the UCL Institute of Ophthalmology.

Our centre is one of 11 national Biomedical Research Centres and is the only one dedicated to eye conditions. Our aim is to provide rapid-track delivery of new diagnostic methods and therapies, developed both internally and in partnership with other organisations.

If you want to know how you can be involved in influencing the design and focus of eye research, please contact us by email at [BRC@moorfields.nhs.uk](mailto:BRC@moorfields.nhs.uk) or by telephone on 020 7253 3411 ext.4658.

Involvement in influencing eye research is different to participating in a clinical research study. If you are keen to participate in a study, please speak to a member of the clinical team you meet when you visit Moorfields Eye Hospital.



# WHO WE ARE



## **Professor Sir Peng Tee Khaw**

- Director of the NIHR Moorfields Biomedical Research Centre (BRC) and of Research and Development
  - Lead for the Regenerative Medicine and Pharmaceuticals research theme
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## **Professor Philip J Luthert**

- Director of the UCL Institute of Ophthalmology (partner to Moorfields Eye Hospital in the NIHR Biomedical Research Centre)
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## **Mr Frank Larkin**

- Deputy Director of the NIHR Moorfields BRC
  - Director of the NIHR Moorfields Clinical Research Facility
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## **Professor Robin Ali**

- Professor of Human Molecular Genetics, UCL Institute of Ophthalmology
- Lead for the Gene Therapy research theme



### **Professor John Marshall**

- Frost Professor of Ophthalmology at UCL Institute of Ophthalmology and Moorfields Eye Hospital
  - Lead for the New Technologies and Devices research theme
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### **Professor Andrew Dick**

- Director of Joint Research at UCL Institute of Ophthalmology and Moorfields Eye Hospital
  - Lead for the Inflammation and Immunotherapy research theme
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### **Professor David Garway-Heath**

- International Glaucoma Association Professor of Ophthalmology, UCL Institute of Ophthalmology
  - Lead for the Visual Assessment and Imaging research theme
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### **Professor Andrew Webster**

- Moorfields Eye Hospital lead for the 100,000 Genomes Project
- Lead for the Genotyping, Phenotyping and Informatics research theme

## The NIHR Moorfields BRC Patient and Public Involvement Team



**Karen Bonstein:** Manager of the NIHR Moorfields BRC

**Debbie Bryant:** Personal Assistant to Professor Sir Peng Tee Khaw

**Catey Bunce:** Principal Statistician

**Richard Cable:** PPE & PPI Research Assistant

**Jocelyn Cammack:** NIHR Moorfields BRC Research Fellow

**Jane Clipston:** NIHR Moorfields BRC Administrator

**Andi Skilton:** PPI & PPE Senior Research Associate Lead

**Ana Quartilho:** Senior Medical Statistician

**Maaret Virtanen:** Undergraduate Education Coordinator

**Meike Walcha-Lu:** Research Technician for Multimedia Innovations

# FOCUS GROUPS

By inviting patients to share their experiences of living with a particular condition researchers are able to gain greater insight into the impact of a condition on daily life. This supports the design of surveys of larger numbers of people to aid in planning research projects with true relevance to people's needs; informs discussions in how to prioritise the questions that need to be answered through a research project and opens up the conversation on the acceptability of the procedures that could form part of the research.

- **100,000 Genomes Project:**

The 100,000 Genomes Project is a national scheme that aims to analyse 100,000 genomes (a person's complete DNA sequence) from participants with cancer, rare disorders and infectious diseases. It has been set up to help gain a better understanding of the genetic causes of these conditions and so improve their diagnosis and treatment. The NIHR Moorfields BRC held a focus group discussion for people with different eye conditions to comment on the project's patient information and consent form. The comments and feedback from our meeting were collated with that of other centres across the UK that conducted similar feedback exercises. The

feedback is currently being analysed so that the project's documents are clear and accessible to those taking part. More information on this national project can be found at [www.genomicsengland.co.uk](http://www.genomicsengland.co.uk)

- **Binocular OCT Imaging Device:**

Patients with AMD and diabetic retinopathy were invited to a focus group to discuss a study that aims to test the usability (i.e. ease of use) of a prototype binocular Optical Coherence Tomography (OCT) imaging device for people with chronic eye diseases.

We welcomed views on the proposed device, how it might be tested amongst patients, the logistics of the usability study and what support individuals might need in order to participate.

Comments were also gathered about the draft patient information sheet. The refined version of this document will be given out to patients recruited to the future study.

This study has been funded for a five-year period by the National Institute for Health Research (NIHR) through a prestigious Clinician Scientist Award to Dr Pearse Keane.



# RESEARCH DAYS

We hold research days for patients, relatives, friends and researchers to learn about people's experiences of different eye conditions; increase awareness of ongoing and future research for those conditions and to consider the priorities and challenges of developing new diagnostics and treatments.

- **Retina Day:**

The NIHR Moorfields BRC supported the running of Retina Day 2015, which was held by the Department of Genetics, UCL Institute of Ophthalmology. Attended by over 100 delegates, the key aims of this event were to hear about and discuss some of the latest innovations in research around gene and stem cell therapies for inherited retinal conditions.

Whilst the day was an opportunity to hear about current and future research, there was also a range of interactive activities and many opportunities for the delegates to share personal

experiences and views about inherited retinal conditions as well as talk with the clinicians and researchers studying these conditions.



- **Birdshot Day:**

This event was the third Birdshot Day held by the Birdshot Uveitis Society. The Society provides support and information for people with this rare, autoimmune condition of the eye (who refer to themselves as “Birdshotters”), which has a spectrum of different symptoms that impact on everyday living. Alongside the 160 delegates, the day attracted many specialist researchers and clinicians who have expertise in this rare retinal condition.



Our PPI team was approached to hold a session about “Living with Birdshot” with the aim of establishing the key impacts of the condition on daily life; how research might help; facilitate communication about Birdshotters’ experiences of the healthcare services; and compile a set of useful tips for living with Birdshot.

We surveyed the Birdshot Uveitis community before the event and Professor Andrew Dick (pictured) presented the results on the day, whilst encouraging many audience members to also share how the condition affects them and to comment on their priorities for research.

- **Blepharospasm Day:**

Mr Daniel Ezra, a Consultant Ophthalmologist and researcher approached the NIHR Moorfields BRC to hold an event looking at blepharospasm, a condition which manifests as uncontrolled muscle contractions around the eyes that can be prolonged and can result in periods of functional vision loss.



Attended by over 100 delegates, the day was the first patient-oriented event in the UK to address this condition, discuss and share experiences of living with blepharospasm and find out how to get involved in research. One of the many outcomes of this event was interest in forming a UK-based patient group for the condition supported by the Dystonia Society.

- **Pemphigoid Day:**

Professor John Dart, a Consultant Ophthalmologist and researcher, along with the Pemfriends patient group asked the NIHR Moorfields BRC for support to hold a day to discuss current treatments and research for a condition called Pemphigoid. This is a group of autoimmune conditions which can affect the eye, skin and mucous membranes of the body.

# Eating for Eye Health

Dr Rosie Gilbert, a Clinical Fellow and PhD research student, embarked on this project after working in the Macular Degeneration clinics and becoming aware of the lack of treatment options available for people with the dry form of age-related macular degeneration (AMD). This project was supported by the NIHR Moorfields BRC and was funded by UCL Public and Cultural Engagement.

Initially, a patient and family member focus group was held at a healthy local restaurant to discuss the relationship between nutrition and eye health, and to find out patients' views on diet. Attendees also sampled a variety of healthy foods. This was followed up by a larger community kitchen project where patients, friends and relatives from our research community socialised and prepared some healthy recipes.

A patient-led information leaflet with recipes and advice discussed throughout this project is being put together to encourage others with an eye condition to eat healthily. It will be available on our BRC website.



# Catching the Light

In 2015, the “Catching the Light” project was our contribution to the United Nations’ 2015 International Year of Light. Over six months, from the longest to the shortest day of the year, patients and their family members as well as staff and students from Moorfields Eye Hospital and the UCL Institute of Ophthalmology came together to make individual glass light catchers and share what light means to them.

Through its focus on the topic of the science of light and its applications, the UN has highlighted that light plays a vital role in our daily lives. It is also an important tool in treating and diagnosing eye conditions ([www.light2015.org](http://www.light2015.org)).

After holding a number of workshops across Moorfields Eye Hospital, the Institute of Ophthalmology and at a number of our Research Days, we displayed the 361 completed Light Catchers in a large window in the Moorfields Eye Hospital public canteen.



In March 2016, we shall return the light catchers to participants as a reminder of the Year of Light and as a reminder of their important role as members of our research community.

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## **What will 2016 bring?**

Capitalising on what we have learnt over the past few years from discussing research with patients, we are keen to widen the involvement of patients in influencing research as well as to continue to meet with groups of patients and researchers to discuss specific topics in detail.

## **So why not get involved?**

If you want to know how you can be involved in influencing research, please contact us by email at [BRC@moorfields.nhs.uk](mailto:BRC@moorfields.nhs.uk) or by telephone on 020 7253 3411 ext.4658.

For more information on these and other projects, and for our latest news and upcoming research days, please visit our website at: [www.brcophthalmology.org](http://www.brcophthalmology.org) and follow us on Twitter: [@MoorfieldsBRC](https://twitter.com/MoorfieldsBRC).