



# Visibility

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## Integrating the patient perspective in glaucoma treatment

**Thanks to support from Moorfields Eye Charity, researchers at Moorfields Eye Hospital and the UCL Institute of Ophthalmology are leading a pioneering project to understand the impact of different treatments on the health-related quality of life (HRQL) for people with glaucoma.**

There are currently over 489,000 people affected by glaucoma in the UK, with more than 11,000 new cases diagnosed each year.

Previous studies have found that glaucoma has a significant and detrimental effect on both physical and psychological HRQL, increasing the risk of falls, road traffic accident and loss of independence and fear of further vision loss.

However, there is very little long term clinical data on the link between HRQL and the

treatment patients receive and so this work has been identified as a priority by the James Lind Alliance, a national partnership organisation which aims to ensure that the perspectives of patients, carers and clinicians are reflected in priority setting for health research.

Currently, most glaucoma

patients are first treated with eye drops to lower pressure. This is normally a life-long course of treatment; however some patients do not like taking them, as they have to be applied daily and can have unpleasant side effects.

*Please turn to page 9 to finish reading this article.*



Gus Gazzard



# Viewpoint

David Probert, Moorfields Eye Hospital's chief executive, welcomes you to this issue of Visibility



It is a great pleasure to welcome you to this issue of Visibility as the chief executive of Moorfields Eye Hospital.

Since I joined Moorfields in April 2016, I have been struck by the enormous professionalism and expertise of our staff and their overriding focus on providing patients with the very highest quality ophthalmic care. I am looking forward to continuing to build on our proud history as a world-leading eye hospital and ensure that our future remains progressive.

Even in the few months I

have been here, there have already been some wonderful examples that demonstrate how Moorfields, in collaboration with our research partner the UCL Institute of Ophthalmology, is leading the way in the fight against eye disease and blindness.

So while these are challenging times for Moorfields, and indeed the NHS, I am optimistic that we will continue to make progress that will be hugely beneficial to our patients and to people with eye disease around the world.

Needless to say, charitable

support has never been more important to the hospital and to the fulfilment of our future ambitions. We are very grateful for everything you do to support us. I have already signed up to Eye to Eye on 12 March 2017 and hope you will join me.

**Thank you for all your support, together we can ensure Moorfields remains at the forefront of ophthalmic care, research and education for the benefit of our patients.**

## News in brief: your update on events at Moorfields

- **May 2016:** Moorfields Eye Charity funding contributes to the development of a test to spot the early stages of sight loss in age-related macular degeneration (AMD). The **Moorfields Acuity Chart** features letters created from fine black and white strips which appear to vanish when they are too small to be recognised.
- **June 2016:** we announced a world-leading collaboration between Moorfields Eye Hospital and Google DeepMind which will use artificial intelligence to analyse eye scans. We hope that automating this process will enable clinicians to detect and treat eye disease faster and more accurately, ultimately helping to avoid cases of preventable eye disease.
- **July 2016:** researchers at Moorfields and Oxford University, led by Dr Fang Ko, reveal they have identified a simple new test, easily incorporated into the standard eye examination, which could identify the early signs of Alzheimer's Disease.
- **August 2016:** research partly funded by Moorfields Eye Charity and led by Professor John Dart identifies a gene that causes eye scarring and a repurposed treatment therapy for the UK's most common cause of blinding conjunctivitis.
- **September 2016:** the Biomedical Research Centre for ophthalmology, based at Moorfields and the UCL Institute of Ophthalmology, receives a major funding award from the National Institute of Health Research, in recognition of its world-leading excellence.

# Make sight your legacy

Last year, gifts left in our supporters' wills contributed over £2million to Moorfields Eye Charity, funding many of our most urgent needs. Moorfields supporter, Andrew Knight, explains why he pledged to leave a gift to Moorfields in his will.

I was admitted to Moorfields in City Road in December 1986 as an emergency. I could not see out of my left eye. My optician quickly diagnosed the problem as a detached retina and recommended I go straight to Moorfields. I was fast-tracked through A&E and admitted within a couple of hours.

At the time I was just 26. I don't think I fully appreciated what I might have lost.

I then underwent two significant operations to correct the problem. The first operation took place a day after my admission, but unfortunately it didn't work. The second operation was successful.

Then in late 2007 my optician diagnosed a cataract in the left eye. This led to further surgery at St Ann's in Tottenham in April 2008. I thought it was wonderful that Moorfields had managed to take the excellent service I had experienced at City Road and transplant it to a satellite location at St Ann's which at first did not look like a hospital with the terrific resources available at City Road. However it was still the same excellent "Moorfields" service.

There were a number of post-operative complications as I was allergic to the steroid eye drop, Maxidex, which caused high pressure in the eye. The new lens had also clouded post-surgery.



Andrew Knight with Lizzie Emilion, Moorfields Eye Charity's legacy manager

Until this was resolved, I had a number of trips to A&E as I had "halos" caused by high pressure in the eye. Whatever time of the day or night I visited, the care was unparalleled. After further appointments at St Ann's, the pressure problem was solved and laser treatment restored the sight to what it was before the operation. However, due to the high pressure issue, I was passed to the Glaucoma Clinic at St Ann's – with Mr Wormald as consultant, to monitor if there had been any damage to the optic nerve. After further visits I was discharged from St Ann's in September 2010, aged 48.

I held the entire Moorfields team in such high esteem, and I felt such enormous gratitude for the care they had given me. By that time I was 48 and then I realised what I could have lost and so I thought it was time to do something. I started then making a regular gift by standing order to Moorfields each month. This began in August 2009 and I have

been pleased to carry it on until now and fully intend to do so in the future.

Being a patient at Moorfields has had a huge impact not only on me but also my wife (who was in fact in December 1986 my girlfriend - so she has been through all my eye problems). As a result we have made provision for the Eye Charity to benefit after we have passed away.

**The care I received at Moorfields over the last 30 years has been fantastic and I feel so lucky that I have been able to access it when I needed it. I hope my gifts enable others to receive the same excellent treatment I have done.**

**We have an audacious vision to create a world beyond blindness.**

It's a big task, and we know that it won't happen soon, but we ask you to join Andrew and help us make this vision your legacy by considering remembering Moorfields Eye Charity in your will.

**To discuss leaving a gift to Moorfields in your will, please contact Lizzie Emilion at [lizzie.emilion@moorfields.nhs.uk](mailto:lizzie.emilion@moorfields.nhs.uk) or on 020 7521 4693.**

# Investing in the ophthalmologists of the future

**“Going to Oregon meant I achieved more than I thought was possible with the funding from Moorfields Eye Charity.”**

One of Moorfields Eye Charity’s aims is to invest in the education of the next generation of world-leading clinicians and researchers at Moorfields, ensuring that the hospital continues to attract and develop the very best doctors, researchers and clinical scientists. In 2015, we were delighted to support Mr Hari Jayaram to take up his Fulbright Scholarship at the Casey Eye Institute in Portland, Oregon.

The scholarship enabled Mr Jayaram to continue his work into novel treatments for glaucoma under the guidance of Professor John Morrison, a pioneer of a new model of experimental glaucoma not currently used in the UK.

This allowed Mr Jayaram to couple his existing knowledge of molecular biology with Professor Morrison’s model. His aim was to understand how raised eye pressure causes damage to the molecular structures of the eye during the early stages of the disease, creating the potential for earlier sight-saving intervention.

While the Fulbright Scholarship covered Mr Jayaram’s living costs, it did not cover research costs, and so the additional funding from Moorfields Eye Charity was vital for him to take up the placement.

Reflecting on his time in the US, Mr Jayaram said: “Going to Oregon meant I achieved

more with the funding from Moorfields Eye Charity than I anticipated. The research culture is very different out there, and my colleagues were incredibly eager to cooperate and collaborate. I was also able to benefit from their fantastic research infrastructure, much of



The Casey Eye Institute in Oregon, where Mr Jayaram worked during his Fulbright Scholarship

which has been made possible by philanthropy.”

The experience also gave him an opportunity to network with colleagues at other ophthalmic research centres, such as the University of Washington in Seattle, where Mr Jayaram collaborated with the engineers developing state-of-the-art optical coherence tomography (OCT) imaging devices to examine the effect of raised pressure on the eye.

“Moorfields is a huge centre for ophthalmology, but it’s good to remember that we’re one of many throughout the world. I’ve bought the links I’ve made back

to London with me, which gives us invaluable contacts with other experts, amplifying the effect of work we’re doing here.”

Now back in London, Mr Jayaram is employed as a clinician-scientist based at both Moorfields Eye Hospital and the UCL Institute of Ophthalmology. This joint post, with his research time underpinned by Moorfields Eye Charity, will enable him to continue some of the work he began in Oregon - developing a laboratory based model of glaucoma for researchers in the UK and establishing his own programme of research.

His time ‘across the pond’

has also given him a new appreciation for the NHS and research in the UK.

“It’s given me a new pride for the NHS. When you think about the number of patients a hospital like Moorfields sees and the standard of care we give them, it’s absolutely amazing. And, of course, the NHS means us researchers have an unparalleled pool of data to draw from, which is unique. Integrating care and research, as we do at Moorfields, is an incredibly powerful tool to address some of the big challenges we’re facing in ophthalmology and I’m excited to be back.”



Mr Hari Jayaram

# Profile: Professor James Bainbridge

Surgeon-scientist James Bainbridge is professor of Retinal Studies at UCL and consultant ophthalmologist at Moorfields Eye Hospital NHS Foundation Trust. He is the clinical lead for the world's first clinical trial of gene therapy for inherited blindness and principal investigator for Europe's first trial of human embryonic stem cells for macular degeneration.



We sat down with the professor to ask him some questions about his work and his experience as a cyclist in the Moorfields Eye Charity RideLondon team for 2016.

**Q: There is a lot of publicity at the moment about gene therapy and stem cell therapies. Could you start by explaining to our readers what they are?**

A: Gene therapy typically involves providing a gene that is otherwise lacking. We use

a vector (a harmless virus) to deliver copies of a gene into the cells that need it.

In some inherited eye diseases (IRDs), a genetic defect leads to the death of the retinal cells. For these conditions we aim to use stem cell therapies to replace these cells. Stem cells are cells

that can grow into any specialised cell type in the body.

**Q: Some of our readers might remember hearing about your work in 2014, when one of our appeal mailings asked for support to develop a gene therapy treatment for LCA4 (a rare form of congenital blindness affecting children). Could you give us an update on how that research is progressing?**

A: I'm very pleased to say that the funds raised mean we are able to manufacture and quality test the vector, and are hopeful that we can begin testing it in children sometime during 2017. We've already identified several potential candidates who would be eligible to participate in the research. This really shows the difference that charitable support can make to our work. We are extremely grateful to the many of you who made this possible, particularly Michael Wade, Barclays Plc, The Cayo Foundation and The Frances and Augustus Newman Foundation.

**Q: It must be amazing to have that sort of impact on some of your patients?**

A: It absolutely is. One example is an eight year old boy who, before his involvement in our trial, struggled to socialise during the winter months because of his night blindness. He would prefer

to stay inside during the evening and was not able to socialise at dusk. It's been very exciting to see how his social life has been transformed by the ability to play football outside in the evening.

**Q: So would you say that your research, focussing on LCA4 and more widely, suggests there's a lot to be hopeful about?**

A: Our initial findings are very encouraging. We are looking at a number of different conditions, including people with genetic disorders, but also with more common conditions like age-related macular degeneration. While lots of our work is still at an experimental stage, it is proving to be safe and well tolerated by patients, but it's still too early to say for how long people may benefit for. Our challenge now is to expand the number of conditions that we can treat and the number of people we can reach.

**Q: Is there anything you're particularly excited about in your research?**

A: I'm excited about so much of our research programme, but if I had to pick one thing it would be the combination of microsurgery and molecular biology which could potentially lead to a range of new interventions that could make a real difference to our patients.

**Q: Alongside your clinical and research responsibilities, you are also the theme lead for diabetes research in the National Institute for Health Research at the Moorfields Biomedical Research Centre. How do you fit it all in?**

A: It's one of the special things about Moorfields that its proximity to the UCL Institute of Ophthalmology means I can balance my clinical and research commitments in the way that I do. The buildings are next to each other, so I can respond to both and move quickly between the two environments. The joint team includes people with a large range of skills, from basic scientists to clinicians, which gives us the expertise required to support our ambitions to develop new treatments and new interventions.

**Q: You signed up to cycle 100 miles for Moorfields in this summer's Prudential RideLondon-Surrey 100. What made you decide to fundraise?**

A: I'd heard good things from Rob Aldous (Moorfields Eye Charity's director of fundraising), and I thought it sounded like a lot of fun. And it was. I'd recommend it to anyone thinking of how they can support Moorfields.

# Major funding for eye research announced

**Moorfields Eye Hospital NHS Foundation Trust and the UCL Institute of Ophthalmology have received a major five year funding award for eye research from the National Institute for Health Research (NIHR), recognising the world-leading excellence of our partnership.**

The joint biomedical research centre (BRC) for ophthalmology, based at Moorfields and the UCL Institute of Ophthalmology, has been awarded £19 million over five years, starting on 1 April 2017.

This announcement follows an application to the Department of Health earlier this summer, which was assessed by an international panel.

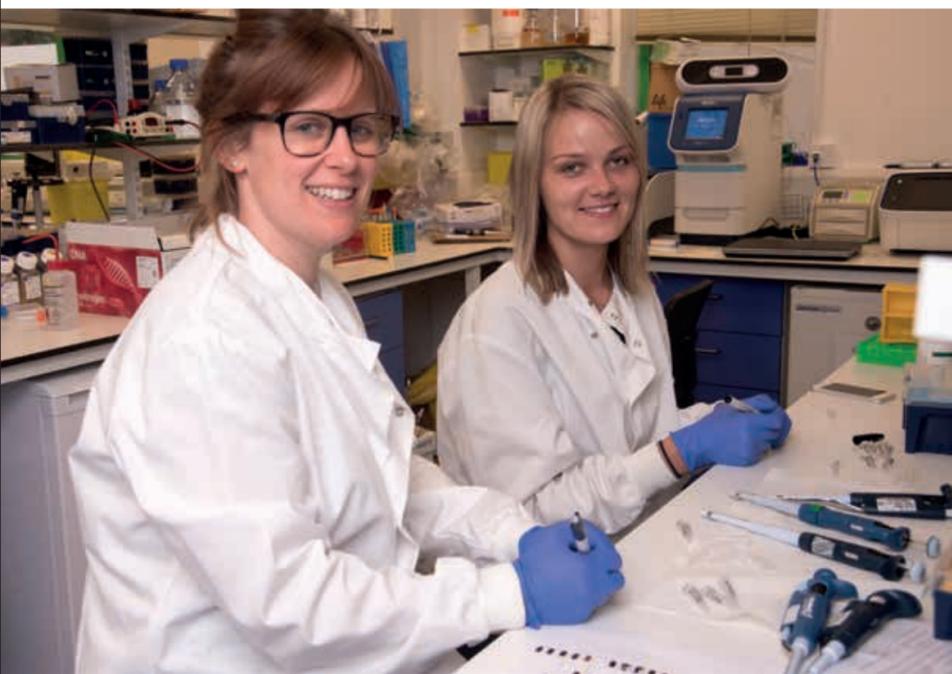
The NIHR funding awards aim to ensure that NHS institutions have the resources they need to remain at the forefront of global

health research, ensuring that partnerships like Moorfields and the Institute of Ophthalmology can continue to push the frontiers of medical science so patients in this country benefit from the very latest treatments and the highest standards of care.

Professor Sir Peng Tee Khaw, Moorfields' director of research and development and director of the BRC, and director of the UCL Institute of Ophthalmology, Professor Andrew Dick said:

**"We are delighted to once again have been awarded a NIHR Biomedical Research Centre. This substantial investment in eye research will enable us to continue to rapidly develop and deliver life-changing treatments for our patients. With sight loss predicted to double by the year 2050, this vital funding for eye research has never been more important. This award recognises our world-leading excellence in translating basic research through to treatments and improvements for patients."**

Welcoming the announcement, Mervyn Walker, chair of Moorfields Eye Charity said: **"The renewal of this important funding is a cause for celebration for Moorfields' patients and for people with sight loss across the UK. Moorfields Eye Charity very much looks to working with the BRC to support their world-leading ophthalmic research programme and I congratulate the team on this significant achievement."**



# Eye to Eye 2017

**Eye to Eye returns on Sunday 12 March 2017 and registration is open now!**

Join hundreds of people walking from Moorfields Eye Hospital to the London Eye to build a world beyond visual impairment.

Eye to Eye is a great way for patients, staff, friends and family to raise funds for Moorfields Eye Charity, and to show their support for or honour a loved one.

Choose between walking 4 or 14 miles and every pound you raise will help fund pioneering research at Moorfields Eye Hospital to help create a future where sight loss is a thing of the past.

There is no minimum sponsorship – just raise as much as you can!

Registration is free for accompanied children under 12 and is just £18 for the 14 mile route and £12 for the four mile route. Every walker will receive a free t-shirt!



**Sign up today**

using the freepost form in at the back of this issue of *Visibility*, at [www.moorfieldseyecharity.org.uk/eye-eye](http://www.moorfieldseyecharity.org.uk/eye-eye) or by calling 020 7566 2486.

*Continued from front cover.*

Now, researchers led by Gus Gazzard, consultant ophthalmic surgeon at Moorfields Eye Hospital and reader in ophthalmology at the UCL Institute of Ophthalmology, are mid-way through a six year investigation to explore whether a form of laser therapy, Selective Laser Trabeculoplasty (SLT), could be an alternative first-treatment and whether being drop-free increases HRQL for patients with glaucoma.

Over 700 patients are currently taking part in the study being run by Moorfields Eye Hospital with a further 250 involved in a sister trial at Zhongshan Ophthalmic Center in China.

**Mr Gazzard says**

"This is a unique opportunity to integrate the patient's perspective into how we treat glaucoma. We hope our findings will help clinicians to answer questions they face every day and will allow our patients to make informed decisions about their treatment. We are extremely grateful to our donors for making this possible."

As well as providing valuable evidence on which is the most effective treatment, the study breaks new ground in including measures of HRQL into its analysis.

# Putting the fun into fundraising

**“There’s currently no treatment, but raising funds for Moorfields is the most positive thing we can do to ensure this won’t always be the case.”**



**Fundraiser Kate Stuzer, whose husband Rob has retinitis pigmentosa, talks about why she fundraises for Moorfields.**

My husband Rob was diagnosed with Retinitis Pigmentosa (RP) at Moorfields in 2013. We were both in our early 30s and expecting our second child.

We were so relieved when we had a diagnosis, but daunted by what the future might have in store so we spent about a year not really telling anyone and coming to terms with what was actually happening.

We decided to try and lead as normal a life as possible and when little things get taken away, like driving and playing football, to take each one as it comes.

Three years on, we now have two girls that keep us busy and we really want to have as much fun as possible!

One thing that was a great relief to me was that Rob was so confident about explaining his situation. He had no qualms about telling people why he can’t see in the dark or can’t see someone

handing back his coat.

His confidence made me feel I could try to do something positive and give something back to Moorfields in the process. The outstanding service and help we receive is some of the best treatment in the world and we feel very privileged to have it.

We thought about all the different fundraising options and being two people who enjoy nothing more than a good party, we decided this was the way forward. What really struck me was that my friends were so supportive and willing to help that it became a team effort. We’ve had two very successful fundraising parties – a Bollywood one last year and a Rio Carnival this year.

For me, it’s like therapy. I love to be busy, and it’s a great comfort to think we’re helping Moorfields. There’s currently no treatment for Rob, but raising funds for Moorfields is the most positive thing we can do to ensure this won’t always be the case.

We have a very simple strategy: choose a theme, find a venue, caterer, DJ and we’re pretty much set. We printed some invitations, and through the power of word of mouth and social media, we sold out!

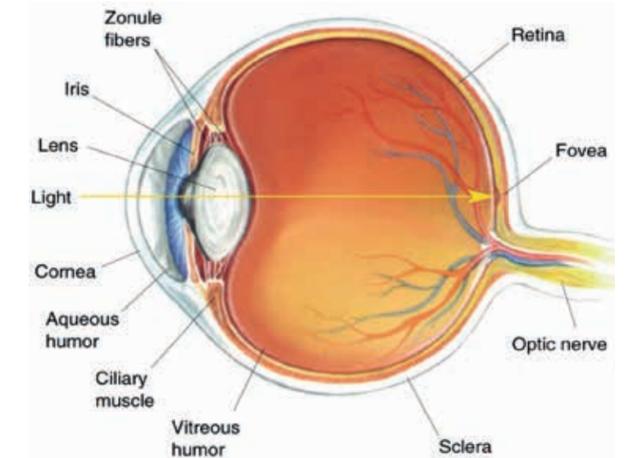
It was a real team effort, with friends helping out with crafts to decorate the venue and organising the raffle. I also popped into two of our local estate agents who were more than happy to sponsor our event. This meant that costs we incurred for venue hire and stocking up our cocktail bar could be offset immediately, creating profit for Moorfields straight away.



**Our Rio Carnival night raised over £2,000 for Moorfields and I can honestly say we enjoyed every minute of it! We’re already planning for 2017.**

## Retinitis Pigmentos

Focus on...



## A world first at Moorfields

The Gene and Cell Therapy Group at the UCL Institute of Ophthalmology, is at the forefront of research in this area, and in 2009 led the world’s first clinical trial of gene therapy to treat inherited blindness.

This trial of RPE65 gene therapy for LCA Type 2 demonstrated the approach to be well tolerated by patients and that it was possible to use gene therapy to improve night blindness for as long as three years.

The team, led by Professor James Bainbridge (see pg 6 of this issue) believes that treating earlier with a more powerful gene may lead to longer-term improvements and benefit other aspects of sight. Funding has now been secured from the UK’s Medical Research Council to start a new clinical trial of RPE65 gene therapy in 2017.

- Retinitis pigmentosa (RP) is an inherited retinal disease (IRD), part of a group of conditions in which a gene defect causes sight impairment by affecting the retina – the layer of light sensitive cells in the eye.
- Around 1 in 3000 people are affected by these currently untreatable conditions.
- IRDs can be caused by defects in over 150 different genes (the body’s operating instructions) that are necessary for normal eyesight.
- Over the last 25 years, research has greatly improved our understanding of how these genetic defects cause IRDs and has allowed us to develop new approaches towards possible treatments.

# Skydiving for Moorfields

**Congratulations to Anne-Marie Riccardi, business support analyst at Moorfields Eye Hospital, who successfully completed a tandem skydive from 12,000 feet for Moorfields Eye Charity!**

Anne-Marie says: "I have to say this was one of the most exhilarating and amazing experiences I have ever had and it was worth every minute of it.

"If anyone else is thinking of doing this – stop thinking just do it! It felt so knowing that a brilliant experience is going towards such a great cause."

If you'd like to take on this exhilarating and thrilling challenge for Moorfields Eye Charity, please do get in contact by emailing [eyecharity@moorfields.nhs.uk](mailto:eyecharity@moorfields.nhs.uk).



Anne-Marie Riccardi

## There's £7,000 worth of prizes to be won!

Tickets are on sale now for the Moorfields Eye Charity Christmas raffle with prizes of £125, or £750, or even £5,000 to be won.

To request your book of tickets simply call the ticket hotline on 0370 085 3799 or go online at [www.moorfieldseyecharity.org.uk/raffle](http://www.moorfieldseyecharity.org.uk/raffle) where you, family and friends can buy tickets right away. Players must be over 18 and entry is only £1 but you'll need to buy **your tickets by 15 December** to be in time for the big draw on 22 December!

We could be calling you to say '*congratulations, you've won...!*' And even if you're not fortunate on this occasion you're nevertheless supporting crucial research, education and patient care at Moorfields.

Over 14,000 players took part in our launch draw last December and raised more than £75,000 for the work of the hospital. So remember to buy your ticket today! Thank you.

## Thank you!

To our intrepid team of Prudential RideLondon-Surrey 100 cyclists who pedalled their way to raise over £47,000 for Moorfields Eye Charity. RideLondon returns on Sunday 30 July 2017. Please email [ride@moorfields.nhs.uk](mailto:ride@moorfields.nhs.uk) to book your place!

