



Visibility Summer 2012



Update on how charitable support is making a difference



UCL Institute of Ophthalmology wins Queen's Anniversary Prize

“Welcome to the second issue of Visibility. Since our last issue there has been much to celebrate at Moorfields and the UCL Institute of Ophthalmology, all of which helps to reinforce our importance as one of the world’s leading centres for eye research and education.

Moorfields’ wide clinical and patient base, combined with the Institute’s size and diversity, gives our partnership a unique ability to translate innovation from the lab to the patient as quickly as possible. The close integration between our two organisations means that our partnership is able to use focused academic research into major clinical problems to generate real and lasting benefit for patients. Together, we have been responsible for several world firsts in new therapies for eye disorders.

In 2008, for example, we were the first centre to undertake human ocular gene therapy (for an inherited retinal disorder called Leber’s Congenital Amaurosis). More recently, our flagship initiative to develop stem cell therapies for the treatment of age-related macular degeneration is set to become one of the first uses of this approach in humans.

Our unique strengths were recognised by the National Institute for Health

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www.moorfields.nhs.uk/eyecharity



Research at Moorfields

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Research (NIHR) last year, when our partnership was awarded Biomedical Research Centre (BRC) status for a further five years. Our application was judged by an international selection panel as being excellent, and we were awarded £26.5 million over five years to sustain and develop our core research.

The NIHR has recently made a further investment of £5.3 million in the BRC to accelerate the transfer of breakthroughs in experimental medicine into treatment trials to benefit patients with eye diseases. This award will be used to fund research doctors, nurses, technicians and facilities.

I was also delighted that the UCL Institute of Ophthalmology was awarded the Queen's Anniversary Prize for Higher and Further Education last November, as part of the UK's national honours system.

The Queen's Anniversary Prizes are the most prestigious form of national recognition open to academic institutions in the UK, and are presented every two years by the Queen in recognition of work by universities and colleges which is judged to be of world-class excellence.

Research sits at the heart of what Moorfields is all about, and will become ever more important as the population ages and eye disease becomes more prevalent. Generous support from respected organisations like the NIHR, and recognition through the honours system, are a vital acknowledgement of the difference we can make to people's lives, and will help us to ensure that Moorfields remains where it should be – at the forefront of developments in eye care. Charitable funding continues to play a key role in the overall delivery of our research strategy and was a contributing factor in obtaining these awards, so thank you very much for your continuing interest and support."

John Pelly, Chief Executive, Moorfields Eye Hospital & Trustee of Moorfields Eye Charity



Development of cell-based therapies to treat retinal diseases

The retina is the light sensitive part of the eye that allows us to see. It harbours six types of nerve cells that send a series of interactive signals to each other when stimulated with light. These signals are then transmitted to the brain via the optic nerve, allowing us to see. Major diseases that lead to blindness in large numbers of people worldwide are caused by damage to the nerve cells of the retina. It is therefore possible that replacement of these nerve cells would potentially restore vision or delay blindness occurring.

Research at the UCL Institute of Ophthalmology and Moorfields Eye Hospital led to the discovery of a population of stem cells in the adult human retina, called Müller stem cells.

These are the same cells that cause spontaneous regeneration of the adult zebrafish retina throughout life. In the laboratory, we can induce human Müller stem cells to become retinal ganglion cells, the type of nerve cells affected in glaucoma; or photoreceptor cells, the light-sensitive nerve cells affected in age-related macular degeneration. Because of these properties, we believe that Müller stem cells constitute a potential source of cells for developing cell-based therapies to treat retinal degenerative diseases.

In the laboratory, we can induce human Müller stem cells to become retinal ganglion cells, the type of nerve cells affected in glaucoma

At present, we are investigating methods to facilitate the survival and integration of nerve cells transplanted into the retina, and are concentrating our efforts on replacing retinal ganglion cells damaged in glaucoma. To further our research towards the pre-clinical stages, our immediate aim is to prepare human Müller stem cells under conditions that comply with therapeutic standards. These cells will then be tested for their safety and efficacy before application into humans. We expect that our approaches will lead to the implementation of new treatments to help people with sight threatening diseases in the near future. This exciting research has recently been awarded a significant grant from the Michael Uren Foundation.

Principal investigator:
Dr G. Astrid Limb UCL

Keratoconus: major study sets sights on new treatment

Keratoconus is a major cause of sight problems in the developed world and one of the most common disorders of the cornea in the UK. It is a progressive condition that is typically diagnosed at adolescence or in young adults, causing sight to deteriorate at an age when poor vision has a major effect on employment opportunities and quality of life. Yet despite its disruptive impact, the causes of keratoconus are not understood.

A debilitating disease

Approximately 55,000 patients are currently being treated or monitored in UK hospitals for the condition, which affects the structure of the cornea – the 'window' at the front of the eye. The onset is usually mild and the effects become progressively worse. In the early stages, vision can be corrected with glasses, but as corneal distortion becomes more severe, special contact lenses are required, which not all patients can tolerate. One in five

patients will eventually require a corneal transplant, and while complications will cause total blindness in less than 1% of patients, significant visual disability is common.

Chance for a breakthrough

But now, following advances in digital corneal imaging and computer-assisted analysis, the condition can be detected in its very early stages when the patient still has useful unaided vision or when their sight can be corrected with glasses. If we can identify the causes of keratoconus and develop new treatment strategies, this early detection offers a vital window of opportunity to stop the progression of the disease before the stage when contact lenses or surgery are required.

Seeking new insights

Moorfields is very pleased to announce a major new study into the causes of keratoconus. Although most patients are unaware of any family history of the

condition, hereditary factors can play a part in almost a quarter of cases. Pinpointing the genes responsible for the condition is essential to improve our understanding. Genetic studies of affected families and patients, combined with studies of keratoconus tissue, will significantly enhance our knowledge of the underlying molecular processes and risks of developing the disease. Our primary goal is to identify the key molecular pathways and translate the findings into better patient care and, ultimately, new treatments that can prevent the progression of this distressing disease.

This important new study has been made possible thanks to a generous grant from the Lanvern Foundation, together with support from the Special Trustees and private funding from a Moorfields consultant.



Patient with Keratoconus, note the protruding cone shape of the cornea at the front of the eye

"Genetic studies of affected families and patients, combined with studies of keratoconus tissue, will significantly enhance our knowledge of the underlying molecular processes and risks of developing the disease."

New boost for research into aniridia

New research into aniridia-related Keratopathy is underway at Moorfields and the UCL Institute of Ophthalmology with the appointment of Dr Victoria Tovell to work with Professor Julie Daniels and the Cells for Sight team. Dr Tovell is working on developing a human model of the aniridia-related Keratopathy disease, following the successful fundraising campaign initiated by the Northumberland-based Chapple family, whose daughter Ella, suffers from aniridia.

Aniridia is an eye disease that affects one in 100,000 people. It can lead to blindness by affecting several parts of the eye. The new research programme will investigate how cell-to-cell communication is disrupted in the

cornea during the progression of aniridia-related keratopathy. The team's ultimate aim is to develop a cell therapy solution to help patients retain their sight for longer.

The Cells for Sight team has had some success in using stem cell therapy to treat those adults with advanced aniridia. Building on the results of that work – and early data from previous stem cell research – the team decided to focus on the role of defective communication between stem cells and their supporting cells in the cornea.

Professor Daniels said: "The research programme is very challenging but if it succeeds it will provide the understanding we need to develop therapies to prevent progression of aniridia-induced corneal

blindness in younger people. The money raised by the Chapple family is a huge boost to our work which has the potential to make a difference to the lives of children like Ella Chapple whose sight will need saving."

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Age Related Macular Degeneration (AMD)

AMD is an eye disease which affects 25 per cent of over-60s in the UK, approximately 3 million people. The London Project to Cure Blindness is seeking to develop a stem cell based therapy for AMD and other retinal conditions with the generous support of the Michael Uren Foundation and other major contributors.

Current treatments for eye diseases have centred largely on standard pharmaceutical drugs that are mainly small molecules, created in processing units and delivered in a drop or tablet form. Recently there have been advances in molecular biology that have allowed treatments with larger more complex molecules such as proteins to be developed. These molecules are usually produced by cells and although they can be created artificially they have a limited lifespan requiring frequent and repeated delivery. The most revolutionary new drug for retinal disease, Lucentis,

which is a protein antibody, needs to be injected into the eye at four weekly intervals for many years.

As cells can constantly create and secrete proteins, we are now looking at placing cells that are programmed to produce a particular therapeutic protein into the eye. The first cell type we are aiming to replace is the retinal pigment epithelium cell (RPE). These cells form a thin sheet lining the inside of the eye, under the retina. A healthy RPE layer is critical to normal sight. These cells, the Retinal Pigment Epithelial Cell, have a great capacity to produce proteins and remain stable in the eye for long periods. The London Project team have created these cells in the lab from both embryonic stem cells and from adult human skin and blood. Their research has established that the placement of the cells in the eye will produce the appropriate antibody or growth factor for many years, until they are removed or destroyed. The intention is to place these cells, which have been

programmed to produce a particular therapeutic protein, in a capsule that is suspended in the eye. The capsule will keep the cells in one place and allow the removal of the cells and capsule if needed. The capsule will be porous enough for the protein to escape through the walls while keeping the cells inside.

This new technology will allow us to deliver a complex molecule in a single delivery while allowing long-term presence of the treatment. If successful, multiple proteins can be expressed from the same cell so that complex combinations of treatments can be delivered in a single cellular capsule.

Stem cells are now being manufactured in the new Sir Jules Thorn Stem Cell Research Unit in preparation for the first clinical trial in humans early in 2013.

Principal Investigators: Mr Lyndon da Cruz and Professor Pete Coffey

New nurse counsellor for Moorfields

Patients with sight-threatening conditions often need extra emotional support to deal with the shock and anxiety that can be triggered by the news. Moorfields Eye Charity is delighted, therefore, to report that it has received funding from the Marie-Louise von Motesiczky Charitable Trust to fund a full-time nurse counsellor to provide patients with specialist information, advice and professional support. Louise De Board took up her new position as the Marie-Louise von Motesiczky Nurse Counsellor in May this year. Louise has been working as an accredited counsellor within the NHS for over 15 years.

This appointment is part of a wider commitment by the hospital to develop an integrated patient support service to provide psychological and emotional support and professional counselling to any patient accessing Moorfields' services at any stage as their sight worsens.

Support for the journey

Patients and their families frequently need more than information and referral to other services. They also require emotional support in a structured environment to help come to terms with their situation without panicking or going on to suffer from depression. We believe that Moorfields should be leading the way in this field as it does in all other aspects of patient care for eye

conditions. Sight loss is a transitional process and it is vital to offer emotional support and counselling services at all stages of this journey – not only at the point of diagnosis.

Extra help for greater peace of mind

Studies estimate that the incidence of depression among people with visual impairment is as high as one in three, with younger people, those in poor general health and those who have experienced a significant negative life event in the previous year tending to be at higher risk. People with depression tend to have more trouble dealing with their everyday activities, regardless of visual changes, which suggests that enabling people to deal with their depression could help them to cope better, even if their vision can't be improved. Jasmine Thombs, Moorfields' existing part-time nurse counsellor, said: "I am so pleased that the hospital will be expanding this vital service when there is such a great need for this help."

Patient perspectives

Barry

Barry has been treated at Moorfields since birth and, following surgery for glaucoma as a child, had managed well with his condition. He was used to living with his restricted vision and enjoyed his life and work. But when he developed a cataract in his only functional eye, his vision started to deteriorate and he began having problems with things he had previously found easy. His GP diagnosed him with depression and, unfortunately, he had to stop work. After a colleague suggested he contact the nurse counsellor at Moorfields, Jasmine was able to help him start a slow recovery. After organising mobility training, Barry was able to return to work.

Barry explains: "It was such a low point for me – I really needed help. The



Nurse Counsellor Louise De Board

regular counsellor offered by my GP just didn't seem to understand." He also told us how Jasmine's specialist experience of working with people with vision loss really made the difference: "Without the support of the counselling service, I don't know how I would have got through it – I think I'd still be at home now."

Denise

Ten years ago, Denise developed a rare eye condition that needed treatment with large doses of steroids. Although these worked well for her eyes, the side effects were devastating. Her weight ballooned to 21 stone and she lost all of her self-confidence. Once her condition stabilised, the medication was reduced and Denise got back to her normal weight. But recently, when her eye flared up again, she was terrified of going back on steroids.

She said: "I was so frightened and anxious about going back to that time again. I felt guilty about needing help when so many people are worse off than me, but I just couldn't cope." Jasmine helped Denise find a counselling service close to home, which she said was brilliant and has made a great difference to how she feels.

Denise summed up: "It's wonderful that people are realising how important this counselling is. It's not just eyes that need help, it's the whole person."



Liz Fisher – Friends General Manager

Liz has been a patient at Moorfields for around 20 years. Her first contact with the Friends of Moorfields was as a volunteer on the Information Desk in 2002, when she also helped with various fundraising activities. Following a career in teaching and management training, Liz joined the staff of the Friends in October 2004 as a part-time administrator and now runs the Friends office on a day-to-day basis. She is especially keen to hear from anyone interested in helping out from time to time with collection days at London train and tube stations. Even an hour or two can be very rewarding and help to make a difference.



David Jewel – Friends volunteer

For over five years, David Jewel has been a Friends volunteer at Moorfields. Having retired from his work as a contemporary crafts manager, he is a firm believer in supporting not-for-profit organisations in as many ways as possible.

David initially came to Moorfields to help out with electronic news production and was soon introduced to the Friends charity, where he now spends a day a week on the Friends Information Desk answering queries from patients and their families. In addition, he lends a hand with the art and jewellery sales that the Friends

frequently organise at the hospital and also took on management and production of the Friends' cookbook.

However, when asked, David is in no doubt that his most important role as a volunteer is simply being able to offer patients the chance to talk informally to someone friendly with a supportive ear to listen – qualities not always readily available in a busy NHS hospital. "As Friends, our unique selling point is time," explains David. "Our role provides a vital link between patients and Moorfields' clinical staff. Knowing this gives me a great deal of satisfaction in what I do as a Friends volunteer."

Your art and jewellery is valuable!

Have you any paintings, prints and other works of art or unwanted jewellery? As well as silver and gold, we welcome all types of jewellery – even broken items can be repaired. Since 2008, the Friends art and jewellery sales have raised over £28,000 through these monthly sales. Come and visit us!

Friends Mini-Mart

Donate your unwanted gifts or other items for our regular mini-marts, including quality modern books, glassware, children's toys and games, DVDs and CDs.

To find out more about the work of the Friends of Moorfields please call 020 7251 1240 or email friends@moorfields.nhs.uk



"...my hope is that research will mean that in the future my vision can be improved and I will one day be able to see my daughter get married..."

Supporting Moorfields Eye Charity

Regular giving to Moorfields - Why Joanne's regular gift counts for so much

For several years, Joanne Thompson Clarke has had an unusual form of glaucoma that was being monitored at her local hospital. But it was only a chance remark about whether she'd be able to drive in the future that made her realise the seriousness of her condition.

Her search for first-class expertise led her to Moorfields where she was advised to have an operation straightaway. Although she was shocked, she knew that surgery offered the best chance of saving her eyesight so she was keen to go ahead as soon as possible. Since then, she has had surgery on both eyes. Now, after many post-operative checks, Joanne is very excited to have a whole six months before her next clinic visit is due. With unequivocal praise for the quality of her care, Joanne told us that the expertise, specialist status and world-class reputation of Moorfields gave her every confidence of receiving the best possible treatment.

Investing today in hope for the future

Because of the uncertainty of her condition, Joanne is especially interested in research programmes, particularly studies into glaucoma treatment and potential therapies to repair damage to the optic nerve. She says: "Following the surgery, people often ask me if my eyes have been 'fixed' and I have to tell them no, they haven't." But she hopes that advances in this field will mean she can see her young children growing up.

To help support research at Moorfields, Joanne has set up a regular donation to Moorfields Eye Charity. She says: "It's so important to support Moorfields Eye Charity. At the moment my condition can only be managed but my hope is that research will mean that in the future my vision can be improved and I will one day be able to see my daughter get married. In a way, my monthly donations to Moorfields are an investment in my future health and probably one of the best wedding presents I could give to my daughter."

Remembering Moorfields in your will



Tim and Priscilla's legacy for future generations

Because Tim and Priscilla Holdsworth consider their sight to be the most precious of the senses, they wanted to make sure that money left in their will would benefit others with sight problems, as Tim explains.

"Developments in modern science, high-tech equipment and research are progressing ever faster and becoming more expensive, so will require even more money in the future. We are sure that Moorfields will continue to be the world leader in both the prevention of sight loss and development of new techniques to restore sight. We hope that gifts such as ours will help to ensure that this happens. It would be a great shame if progress was held up due to lack of funds – those with sight problems often wish they could be solved immediately, not some time in the future.

Remembering Moorfields in our will has been a simple way to demonstrate that we care about Moorfields as they cared for us, ensuring that our legacy will help make positive things happen for the next generations. We want to encourage more people to leave gifts in their wills to Moorfields Eye Charity for the restoration of that most important of our senses – our sight."

