Marching for Moorfields

More than 500 Moorfields supporters took part in Moorfields Eye Charity’s new mass-participation event Eye to Eye on Sunday 22 March to raise awareness of and vital funds for the hospital.

Patients, their friends and family, and Moorfields staff – including chief executive John Pelly and medical director Declan Flanagan – put on their walking (and running!) shoes to take on either a four- or 14-mile route around London.

Starting at the hospital, the four-mile route passed through much of the City of London and continued west onto the Thames Path National Trail, while those on the extended walk also enjoyed Hyde Park and Regent’s Park. Participants set off at staggered times throughout the morning and early afternoon, and regular pit stops kept them refuelled and revitalised.

Many supporters dressed up for the occasion — some donning eye-related headwear, others wearing statement costumes such as traditional nurse attire, and one team came equipped with ski poles to practise Nordic walking. Walkers of all ages and abilities made their way at their own pace to the finish line near the London Eye on the Southbank, and were greeted on arrival by the Moorfields fundraising team, and a celebratory party of tea and cake.

The event has raised funds for life-changing treatment and research in several areas, including glaucoma, age-related macular degeneration, corneal and ocular surface diseases and children’s eye conditions.

Walker and patient Esther Elliott explained her reasons for taking part: “I was diagnosed with keratoconus (a disorder that causes structural changes within the cornea) when I was a teenager, and I received my second corneal transplant in March. I decided to take part because I feel incredibly lucky to be treated at Moorfields. It has been wonderful meeting other walkers who share similar experiences.”

Thank you to everyone who took part and helped raise more than £105,500.

Registration for next year’s event, which will take place on Sunday 13 March, is now open. For further information or to sign-up, please see the response form attached to the newsletter, email eye2eye@moorfields.nhs.uk or call 020 7566 2486.
Moorfields has grown significantly during my time here; we now treat people at 22 locations in and around London, which means that we are able to bring expert care closer to patients’ homes. Despite the challenging climate, we continue to provide the highest levels of ophthalmic care and are committed to sustaining and building on our pioneering history, ensuring we remain a world-class centre of excellence for ophthalmic research and education.

“Our supporters are vital to our work as we strive to provide the best possible care for our patients”

I have greatly enjoyed my involvement with Moorfields Eye Charity since its launch in May 2011, which was attended by Ann Widdecombe. Reflecting the special bond that many of our patients and members feel towards the hospital, I have been struck by the enormous number of you that have responded to our charity’s appeals over the years and have supported us in other ways. It has been an absolute pleasure to meet some of you during my time at Moorfields and to have the chance to thank you personally for your support.

Over recent months, there have been various stories in the media about the way some charities carry out their fundraising and it seems timely to reassure you about our approach and share with you our supporter promise. Our supporters are vital to our work as we strive to provide the best possible care for our patients, educate the researchers and clinicians of tomorrow, and support cutting-edge research.

Leaving Moorfields will inevitably be a sad day for me, but I plan to carry on supporting Moorfields Eye Charity. I am also looking forward to next year’s Eye to Eye event on Sunday 13 March and hope to see many of you there. In the meantime, I would like to take this opportunity to thank you again for your ongoing interest and support of this wonderful hospital, which I am confident will continue to go from strength to strength.

Moorfields Eye Charity’s supporter promise

- We value every gift we receive, and seek to acknowledge and send thanks for all donations in a timely manner
- We’ll share news about Moorfields Eye Hospital and the UCL Institute of Ophthalmology, the hospital’s research partner. We will also keep you informed about how charitable donations are benefitting patients and people with sight problems further afield
- We will always take action if any external supplier acting on behalf of Moorfields Eye Charity fails to meet our standards
- When we get things wrong, we’ll be up front about our mistakes, say sorry and try to fix them
- We will reflect your wishes, so if you ask us not to contact you we won’t, unless it’s a legal requirement
- We will never sell your data or share it (other than with our university partner UCL, for information only) without your permission
- We will always check first that you are happy to speak to us, if we phone, and that it is a convenient time to call
Prioritising patient support

Thanks to vital charitable support, Moorfields’ integrated patient support service, launched in 2012, is now a well-established element of the care we provide for patients, improving the patient experience by offering vital psychological and emotional support, and professional counselling.

The timing of emotional support can be crucial for patients receiving bad news and there is a need to continue to develop this service to ensure that this support is available across the hospital’s entire network. Tracy Luckett, Moorfields’ director of nursing and allied health professions, is committed to ensuring that every patient who attends Moorfields has access to this support, and explains plans for developing the service:

“The existing service would not have been possible without charitable funding, and it is fantastic that the Marie-Louise von Motesiczky Charitable Trust has agreed to extend their support by funding an emotional support coordinator post covering Moorfields locations in east London as part of a two-year pilot.

“The role will involve leading a team of emotional support volunteers located in all the clinical areas across the directorate. My hope is that if the pilot is successful, we can replicate this network of emotional support workers across the other three directorates, so that all patients have access to this support where they are being treated.”

In addition to the funding being provided by the Marie-Louise von Motesiczky Charitable Trust, Moorfields is also very grateful to the Thomas Pocklington Trust for agreeing to recruit the volunteer support workers and fund their training programme. The pilot is expected to get underway this autumn.

First-class fellow

Moorfields medical retina fellow Pearse Keane has been hailed as one of the ‘top 40 under 40’ in The Ophthalmologist magazine’s 2015 power list. The line-up recognises young, up-and-coming ophthalmologists expected to rise to the top of their field. Pearse is ranked fourth and is commended for his internationally renowned expertise in optical coherence tomography (OCT) imaging research and his many papers on medical retina published in high-ranking journals.

This achievement comes just a few months after he became the first ophthalmologist in the UK to be awarded the prestigious National Institute of Health Research (NIHR) clinician scientist award.
Breaking new ground in cataract surgery

Thanks to a generous donor, Moorfields has bought a femtosecond laser which will be used in a research trial funded by the National Institute of Health Research.

The trial will assess the benefits of the latest high-precision laser technology in routine NHS cataract operations and it is the first time this type of surgery has been made widely available on the NHS.

Age-related cataracts are the leading cause of visual impairment in the world and cataract surgery is the most commonly performed eye operation worldwide. One in three people in the UK is predicted to require treatment at some stage, with 300,000 cataract operations taking place in the UK each year. Moorfields performs more than 15,000 cataract procedures a year.

Moorfields consultant ophthalmologist Mark Wilkins, who is leading the research, said: “Although the technology has existed for some time, it has generally only been available for private patients. We are delighted to have the opportunity to extend this technology to NHS patients and are extremely grateful to the donor for his generous support”.

Appeal paves the way for revolutionary genetics research

Thanks to the generous response to our Christmas 2014 appeal, work is underway to solve the genetic cause of inherited conditions affecting the cornea (the front part of the eye).

Research is being conducted with our academic partners at the UCL Institute of Ophthalmology, and is being carried out with patients who have volunteered for the tests. The response from patients and their families who have attended Moorfields’ new genetics clinic has been very positive.

Testing has so far exceeded expectations and has identified the genetic cause for 11 different types of corneal dystrophy in 95 families. This means that specialists are able to advise more accurately on prognoses and test other family members to see if they might be at risk of developing the condition. Research findings also unlock clues about inherited corneal disease, about which little is known.

Currently, the only way to treat these conditions is by means of corneal grafts, which involves surgery. This new research data means that it is possible to make a more accurate assessment of which genes are causing different conditions. This will help direct future research and facilitate the development of new treatments that will, it is hoped, be carried out quickly and simply, and without the need for surgery.

Genetic testing is planned to run until May next year and will include as many patients and families as possible.
Leaving a legacy

Moorfields Eye Charity is grateful to everyone who thinks of using their will to support the work of the hospital as it strives to help the growing number of people with eye conditions throughout the UK and the rest of the world.

Director of fundraising Rob Aldous explains why he has made provisions for Moorfields Eye Charity in his will: “I have worked for Moorfields for more than 10 years now and I feel privileged to work with some very inspiring people who are committed to helping our patients and developing new treatments for blinding conditions like glaucoma, retinitis pigmentosa and age-related macular degeneration.

“Putting Moorfields Eye Charity in my will was straightforward and enables me to make a more significant contribution to a cause I care deeply about. I would encourage everyone who feels passionately about our work to remember Moorfields Eye Charity when you make or next update your will. Charitable donations continue to play a crucial role in the work of the hospital.”

A legacy can be more than just money. As well as generously helping to fund our work, you could also directly help to save someone’s sight (see below). Moorfields undertakes hundreds of corneal transplants each year, none of which would be possible without the kindness and generosity of tissue donors. Eye donation saves sight and enables research into new treatments.

Leaving a legacy to Moorfields is an important decision, but it doesn’t have to be complicated. Information, support and advice is available to make the process as easy as possible. If you have a question about leaving a gift in your will, please contact Lizzie: 020 7521 4623, elizabeth.petrie@moorfields.nhs.uk.

YesEyeCan campaign – we need your support

Our YesEyeCan campaign, led by the Moorfields Lions Eye Bank, took place in June to raise awareness of the importance of eye donation for crucial sight-saving surgery and to encourage more people to sign-up to the organ donation register.

The number of eye donors in and around London has decreased over recent years and there is often a shortage of tissue available for transplant. Without tissue many patients cannot have an alternative therapy or treatment for their eye condition.

Agreeing to donate your eyes after your death could potentially restore or improve the vision of up to 10 patients. Donated tissue helped Moorfields carry out 840 corneal transplants in 2014, perform 240 operations on glaucoma patients and made an invaluable contribution to a number of research projects. However, a 25 per cent drop in donors last year means donations are becoming scarcer and increasingly expensive to source.

See Esther Elliot’s story and find out more: www.moorfields.nhs.uk/yes-eye-can.
Our story

Eight-year-old Ella Chapple has a rare genetic condition called aniridia. Her family’s fundraising efforts for Moorfields have to date raised more than £100,000 to support crucial research into the condition that could help Ella, and children like her, regain some vision in the future. Mum Elly shares Ella’s story.

When our daughter Ella was born in 2006, we were initially told that she had Down’s syndrome. However, results of genetic testing told us she had a chromosome disorder and a rare eye condition called aniridia, which means she was born without irises. It was such a frightening time for us – what was meant to be a joyous occasion had become a journey into the terrifying unknown.

When Ella was two years old, she did something we never thought we would see – she stood up and walked. Unfortunately, though, our happiness was short lived; a month later, bilateral lumps were spotted during a routine scan of her kidneys. While we knew cancer was a possibility from day one, we thought she had bypassed that particular horror. Nothing can prepare you for your child having chemotherapy and major surgery. That year – 2009 – was a very hard one for all of us, but Ella’s strength of character and resolve shone through, and shortly after her third birthday she had a clear CT scan. Ella coped with more in the first three years of her life than most of us confront in an entire lifetime. She did so with determination, good humour and the energy of an Olympic athlete. We have learned so much from our daughter and have grown immeasurably due to her being in our life.

Last year, Ella’s retinas detached (due to head banging and stress caused by deafblindness – something that was not diagnosed until April 2014) and she lost her vision, despite five operations to try and save her sight. I knew that loss of sight was a possibility, but I never thought it would actually happen to Ella. It has been a rollercoaster ride, but Ella is fighting back against her tough ordeal and is going from strength to strength.

My husband James was one of the 20-strong Fairy Queen Dream Team that recently took part in the Prudential RideLondon–Surrey 100 for Moorfields on 2 August [read more about the event on page 8]. James has taken part in...
the event for the past three years, raising money for Moorfields and Aniridia Network UK. This year the team was successful in raising more than £10,000, and Ella gave me a thumbs up after I told her that her daddy had finished and everything went well!

Ella is now receiving specialist support from deafblind “intervenors”, which Elly describes as a “human form of a guide dog” and her “eyes and ears”. The impact has been significant – it has enabled Ella to regain her confidence, and she now has the imperative trust relationships that she needs to learn, develop, communicate and be in the world as a deafblind child.

www.aniridia.org.uk

The Fairy Queen Dream Team at the Prudential RideLondon–Surrey 100 in August 2015

Latest aniridia research at Moorfields

The funds that have been raised in Ella’s name are supporting research led by professor Julie Daniels and her team at Moorfields and the UCL Institute of Ophthalmology to help create, for the first time, a human tissue model of aniridia-related keratopathy (ARK) to be used to understand the disease better and thereby develop new treatments. A significant breakthrough has been their ability to grow ARK cells and use them in experiments to mimic aspects of the disease process. It is anticipated that this will lead to the development of new treatments for aniridia.

Aniridia

- Aniridia is a rare medical condition affecting the eyes. It is congenital (present at birth). Most people with aniridia have all or part of their irises (the coloured part of the eye) missing, which is what gives the condition its name. It also causes many parts of the eye to be under-developed, such as the optic nerve and macular/fovea. This results in most people with aniridia having some reduction in their level of vision
- People with aniridia may also develop other eye conditions. Aniridia and these associated conditions affect everyone differently. So while some people with aniridia are partially sighted or blind, others may have near normal sight
- Aniridia is a genetic condition. It is usually due to an abnormality in a gene called PAX6. This can be inherited from a parent or can be a result of a mutation when a baby is conceived
- Aniridia may also occur among other conditions as part of another genetic condition known as WAGR/11p deletion syndrome
Step into action for Moorfields
Sunday 13 March 2016

If you would like to take part in Eye to Eye, please complete and return this FREEPOST form.

Registration costs just £18 for the 14-mile route and £12 for the four-mile route. There is no minimum sponsorship – just raise as much as you can!

Please complete one form per adult and fill in all sections. If you require further copies of this form, call 020 7566 2486 or email: eye2eye@moorfields.nhs.uk
Alternatively, you can fill this form in online at: www.moorfields.nhs.uk/eye2eye

Participant details
Title: First name:
Surname:
Age: Gender:
Date of birth:
Team name:
(if you intend to take part in a team, please provide the team name so that we can group you together on the day)
Address: Postcode:
Phone number:
(Mobile preferred, in case we need to contact you on the day)
Email address:

I am happy for Moorfields Eye Charity to contact me by email (please tick).
Next of kin: Next of kin’s phone number:

I would like the funds I raise to go towards research into (please tick one):

- Glaucoma
- Age-related macular degeneration
- Diabetic retinopathy
- Retinal diseases
- Cornea and ocular surface diseases
- Children’s eye conditions
- Inherited eye disease/rare diseases
- Wherever the need is greatest

Registration fees can be paid by cheque or credit card. Please enclose a cheque with this form, made payable to “Moorfields Eye Charity”. To pay by credit/debit card, please complete the details below or call 020 7566 2486

Please tick as appropriate:

- 14 mile route (£18 per person)
- 4 mile route (£12 per person)
- NB Free place for under 12s with every adult place on the 4 mile route

Name of participant under 12:

- I would like to include a donation of £ —— to Moorfields Eye Charity
- I do not wish to take part but would like to donate £ —— to Moorfields Eye Charity

Debit/credit card details:

Card type (please note we cannot accept AMEX):

Card number:

Security code (last three digits on the back of the card):

Issue number (switch only):

Start date: Expiry date:

Signature:

Date:

All the information you provide us with will be treated in the strictest confidence by Moorfields Eye Charity in line with the Data Protection Act 1998. However, we would like to keep you updated on our work and developments in eye care. If you do not wish to receive any further information from us please tick the box.

Please note: Registration fees are non-refundable.

If you require this form in a larger font please call 020 7566 2486.

Organised by: Sponsored by:

Discover Adventure Moorfields Private Eye Hospital

The information provided on this form will be shared with our event partner Discover Adventure, as operator of the challenge. It will not be shared with any other parties without your express permission.

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Moorfields Eye Charity
162 City Road
London
EC1V 2PD
Pedal power

More than 25,000 cyclists took part in the third Prudential RideLondon–Surrey 100 – Europe’s biggest sportive – on Sunday 2 August. Unlike at last year’s event, which saw soggy cyclists battling through torrential downpours, participants enjoyed blue skies and glorious sunshine throughout the day.

Some familiar faces were part of the 70-strong Moorfields Eye Charity team: Moorfields’ consultant ophthalmologist Keith Barton, who has taken part in all three RideLondon events to date; the Fairy Queen Dream Team, who were raising money for aniridia research (see pages 6–7); and cycling enthusiast and Moorfields’ director of fundraising Rob Aldous (pictured). Last year, nearly £80,000 was raised by those who took part for Moorfields Eye Charity and we hope to reach a similar figure this year. A huge thank you to everyone who took part, donated to this year’s event and provided much-needed moral support (and sandwiches) for participants.

Next year’s event is scheduled to take part on Sunday 31 July 2016. If you would like to join the Moorfields Eye Charity team, or find out more about the event, contact Nico: 020 7566 2486 or email eyecharity@moorfields.nhs.uk.

Eyes on the prize!

Moorfields Eye Charity is launching its first ever prize draw this autumn to raise money to support the work of the hospital. We plan to hold two draws annually and our aim is to raise more than £100,000 a year.

The draw offers a fun opportunity for our supporters, and their families and friends, to help our work. Tickets cost just £1 each and there will be a guaranteed £7,000 in prizes to be won in each draw. And, of course, the real prize will be the money we raise for Moorfields, our patients and people with eye disease around the world.

When you receive your tickets, please take part and encourage your family and friends to do the same.

First prize is £5,000. There is a second prize of £750 and 10 runner-up prizes of £125. The draw will be made on 22 December this year.

Good luck – you could be one of our very first winners!