

People's sight matters



Moorfields  
Eye Charity

# Visibility

Autumn 2023 | Issue 22



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# Viewpoint

Robert Dufton, our chief executive

Welcome to our autumn issue of Visibility. As the seasons change, we're looking forward to more major developments with Oriel following the breaking ground celebrations and the start of construction. We will be sharing more news of our donors supporting this new global centre for eye health in the upcoming months.

We're delighted to announce a partnership with the Medical Research Foundation, which will invest £1.7 million of funding into childhood and adolescent eye health research. This first-of-its-kind funding will significantly impact a massively underfunded area and change the lives of children with sight loss worldwide.

In this issue, we share news on projects we're funding, including research into aniridia – a rare genetic eye disorder, and the elevated crowding effect in nystagmus, as well as the innovation grants transforming specialist eye services at Moorfields. In collaboration with the experts at Moorfields, we give insights into how children's eyes develop and tips for parents.

You can read Chris' incredible story – a patient at Moorfields since he was one month old and now an accomplished Taekwondo athlete and coach. Moorfields' treatment not only saved his sight but empowered him to live his best life.

Eye to Eye 2024 is coming soon – find out more and how you can register your interest.

Thanks to your support, we can invest in so much more at Moorfields and UCL. Thank you for everything you do, whether donating to an appeal, doing your own fundraising, playing the lottery or leaving a gift in your will.

We hope you enjoy reading this issue.



Moorfields Eye Charity staff before the Moorfields' Stars awards ceremony

# Our news



## Oriel breaks ground

We're very excited that with our partners Moorfields Eye Hospital NHS Foundation Trust and the UCL Institute of Ophthalmology, we held a special breaking ground celebration in the summer. This marked the start of construction to build Oriel, the new centre for eye care, research and education in St Pancras, and future home for the partners.

We were delighted to be joined at this important milestone by key donors who are supporting Oriel. Oriel will enable closer

collaborative working between clinicians and researchers which will bring new treatments to patients faster than ever before.

A £300 million contract has been awarded to Bouygues UK to build the new centre, which will open in 2027. Demolition of six buildings on the Oriel site is complete, and construction of the 10-storey, 47,000 square metre centre has started.

**"We were delighted to invite our generous leadership donors to the breaking ground event. It gave us an opportunity to thank them for their support. Philanthropy is a key part of the Oriel funding mix and has a vital role in securing the future of eye health on a global scale."**

Robert Dufton, chief executive, Moorfields Eye Charity



Scan here to watch demolition on the Oriel site

## Archaeological finds on the Oriel site

A team of archaeologists from the Museum of London Archaeology have been working on the Oriel site and have uncovered the foundations of a 19th-century workhouse which give fascinating insights into the site's history.

[oriel-london.org.uk/the-big-reveal-archaeological-update-from-the-oriel-site/](http://oriel-london.org.uk/the-big-reveal-archaeological-update-from-the-oriel-site/)



Scan here to read the blog on the Oriel website

Thank you to our donors to date. If you'd like to find out how you can get involved, contact Rachel Jones at [rachel.jones310@nhs.net](mailto:rachel.jones310@nhs.net) or call 020 7521 4610.

## £1.7 million to support children's eye health

We're delighted to be working in partnership with the Medical Research Foundation on a funding initiative investing £1.7 million to support research into childhood and adolescent eye health.

Globally, at least 450 million children have a sight condition that needs treatment\*. This research will increase our understanding of eye health and

disease in children and adolescents, which could lead to improvements in diagnosis and treatments.

This is a fantastic opportunity to help save sight and transform the lives of millions of children worldwide.

Applications for grants are open via the Medical Research Foundation.

**Help us raise £500,000 for this project to support children's eye health research at Moorfields and UCL – visit [moorfieldseyecharity.org.uk/help-us-save-childrens-sight](https://moorfieldseyecharity.org.uk/help-us-save-childrens-sight)**

\* IAPB, Focus on Child Eye Health 2022



## Young people's voices – eyeYPAG

The Young Persons' Advisory Group (eyeYPAG) allows young people aged 8-16 to get involved with research at Moorfields. This is the UK's first young persons' advisory group for children with eye conditions. The eyeYPAG members co-produced an evaluation report and found

eyeYPAG to be empowering for everyone involved. The benefits for young people included learning about different eye conditions, making a difference in research, developing new skills and meeting new people. Watch the video about eyeYPAG on the charity's website.



eyeYPAG is supported by the Moorfields Biomedical Research Centre, Moorfields Eye Charity and Santen.

"I love meeting new people interested in the same things as me."

eyeYPAG member

"[Young people's involvement] makes research better, but also children and young people have a right to have a voice, and a say in things that affect them."

Dr Vijay Tailor, orthoptist, Moorfields Eye Hospital

Read eyeYPAG's blog at [generationr.org.uk/eye-ypag/](https://generationr.org.uk/eye-ypag/)

If you'd like to join the group, please email [moorfieldsbrc@nihr.ac.uk](mailto:moorfieldsbrc@nihr.ac.uk)

## Medical illustrator's legacy

The celebrated medical illustrator Terry Tarrant, who worked at Moorfields and the UCL Institute of Ophthalmology, has passed away aged 93. Terry painted beautiful images of the eye that transcended mere technical excellence.

In 1948, Terry joined the newly founded Institute of Ophthalmology, where he worked for almost four decades, and then the High Holborn branch of Moorfields until his retirement.

The joint Moorfields and Institute library has preserved and catalogued over a thousand of Terry's paintings, and they are the brightest jewels in their collection.

Donations at Terry's funeral were for Moorfields Eye Charity. Our thoughts are with his family and friends.



## Fundraising news

### Year of fundraising challenges!

Sarah Canning, head of optometry at Moorfields Eye Hospital, is a fundraising superstar! She is almost half way through a year of outstanding fundraising challenges to support Moorfields Eye Charity and Heart Research UK. This includes a night climb of Snowdon, a dawn-to-dusk canoe challenge on the Wye River, an epic swim challenge around the Scilly Isles and Eye to Eye 2023.

Sarah Canning was the winner of the Moorfields Eye Charity Champion award at Moorfields' Stars 2023 - celebrating staff achievements over the last year.



### Eye to Eye in June 2024

For its 10th anniversary, big news for Eye to Eye as it's on the move from March to 23 June 2024 - bookings open in January.

Walk solo or with friends, family, colleagues and canine companions around the historic streets of London to support Moorfields and UCL and make a difference to the future of eye health.

Visit [moorfieldseyecharity.org.uk/EyeToEye](https://moorfieldseyecharity.org.uk/EyeToEye) to register your interest



1st  
£5,000  
prize

2nd  
£750  
prize

3rd  
£125  
prizes  
x10

### Could you be our next big Christmas winner?

Enter our Christmas raffle and make a difference to the lives of people with sight loss, both today and in the future.

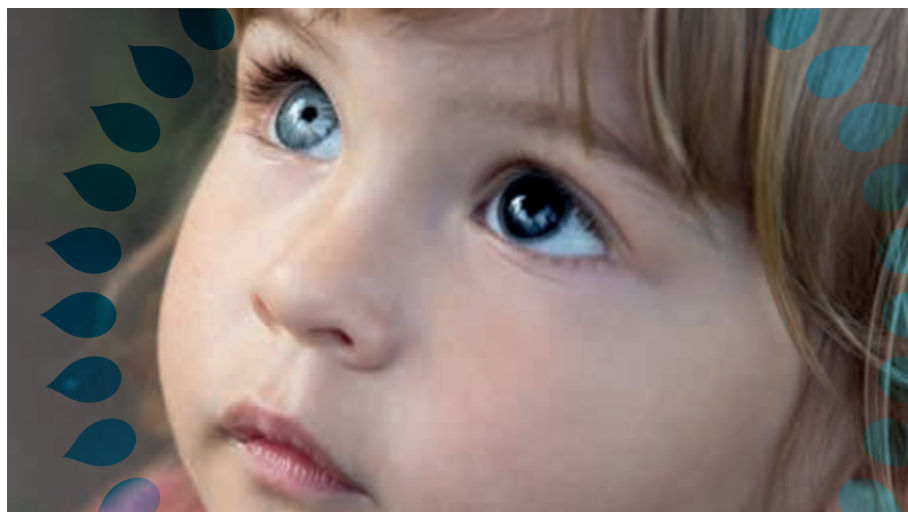
Enter by 8 December

Draw takes place on 14 December

See the pull-out section for details

## New treatments for aniridia

Aniridia is a rare genetic eye disorder that results in complete or partial underdevelopment of the iris and the fovea. This affects the appearance and function of the eye. Later complications such as cataracts, glaucoma and corneal opacity can lead to progressive vision loss.



We've supported Mariya Moosajee, UCL professor of molecular ophthalmology and consultant ophthalmologist at Moorfields Eye Hospital, and her team to test potential pharmacological treatment options for this currently incurable disease.

### What is Aniridia?

Aniridia is a condition where parts of the eye, including the iris, fovea and optic nerve, do not form correctly. The iris is the coloured front part of the eye, and the fovea is the area of central vision at the back of the eye.

### Causes of aniridia

Aniridia is mainly caused by mutations in the *PAX6* gene, which has a fundamental role in the development and maintenance of eyes. Around 40% of these mutations introduce an abnormal stop signal in the gene instructions.



**“The challenge is to find a way to override these stop signals so fully formed and functional protein can be produced and enable normal eye development.”**

**Professor Mariya Moosajee**



**Between 1 in 40,000 to 100,000 births are affected by aniridia**

### Testing treatments

The team tested two drugs, ataluren and amlexanox, which can override abnormal stop signals in the gene to promote protein production.

Treatment with amlexanox increased levels of fully formed and functional *PAX6* protein four-fold in the aniridia human cell models. The results of this study are published in the Molecular Therapy Nucleic Acids journal.

Further work will focus on testing whether amlexanox and other, similar drugs, such as 2,6-diaminopurine (DAP), can improve the development and function of eye cells.

If successful, amlexanox could be repurposed as a treatment for aniridia, which would potentially benefit patients with mutations in the *PAX6* gene in the future.

## Nystagmus and the crowding effect

People with infantile nystagmus syndrome are unable to control their eye movements. This near-constant movement of the visual world makes their vision blurry and impairs everyday tasks like reading and finding people in crowds.



**90% of nystagmus cases are identified by six months of age**



We're supporting Dr John Greenwood, UCL experimental psychologist, and Dr Vijay Tailor, an orthoptist at Moorfields Eye Hospital, to advance research into nystagmus and understand how crowding impacts patients' lives.

### The potential

We know that adults with nystagmus experience elevated crowding, but no one has ever tested this effect in children with nystagmus. By establishing the presence and level of crowding effects in children with nystagmus, we can see whether nystagmus changes the brain. If nystagmus does change the brain, then the development of this deficit should cause the effect of crowding to increase with age. The alternative is that the eye movements themselves make objects hard to see in clutter, which should cause a constant crowding effect across all ages. Suppose the results show that crowding effects are elevated in children and associated with changes in the brain. In that case, this will ultimately improve the screening for nystagmus and provide insights for developing new treatments and enhanced support for patients.

### What is infantile nystagmus syndrome?

Infantile nystagmus syndrome (INS) is a visual disorder characterised by rhythmic and involuntary eye movements that develop around birth and persist throughout adulthood.

The most widely characterised visual deficit in nystagmus is reduced acuity - the resolution of vision.

Vision in nystagmus is further disrupted by elevations in 'crowding', an effect where objects, like letters that are usually clear and visible in isolation, become difficult to recognise in clutter.

### New research

Building on the results of Dr Tailor's PhD project studying how elevated visual crowding affects nystagmus patients' vision in adulthood, we're supporting a follow-on study by Dr Greenwood and Dr Tailor. It will measure acuity (resolution) and crowding in children with infantile nystagmus. This is the first study of crowding in nystagmus with children.

This research aims to gauge the degree of elevation in crowding in nystagmus compared to typical development. This is important to develop new treatments and better understand the visual experience of children with nystagmus.



**Dr John Greenwood**



**Dr Vijay Tailor**

**This project is supported by Moorfields Eye Charity and with funding from the Nystagmus Network supporters.**

We're proud to support innovations at Moorfields and UCL, which have helped propel this partnership to world-leading status. We've recently awarded two innovation grants to strengthen the delivery of specialist treatments 'above and beyond' what the NHS supports.

## Transforming specialist eye care

### Glaucoma

Glaucoma is a chronic disease that requires life-long surveillance. There is an increasing demand on consultant-led clinics with an ageing population and more treatment options. The diagnostic clinics at Moorfields are designed to address this but currently are only running at 68% capacity and previous studies have shown up to a 20% rate of missing glaucoma progression. One reason for this is that the reviewing clinician needs to examine the eye, which is particularly important in post-surgical monitoring of glaucoma patients.

Moorfields has piloted introducing smartphone photography to these clinics. Technicians can be trained to take detailed photographs of the front of the

eye, which alongside existing investigations allow the clinicians to clearly see the health of the anterior segment and examine surgical sites asynchronously. The pilot results showed that including photographs changed management in a quarter of patients.

The results of this pilot supported a successful grant application to Moorfields Eye Charity to roll this out further and to support a mobile friendly interface in OpenEyes. The project is led by Dr Peter Thomas, director of digital medicine, and Hari Jayaram, glaucoma consultant. Their team include Caroline Kilduff, Dhakshayini Muhundhakumar and Usha Halai at Moorfields Eye Hospital.

The process is also low cost and therefore adaptable and scalable across eye care.

### Hypotony

Mr Harry Petrushkin, a uveitis consultant at Moorfields Eye Hospital, is working with colleagues within the hospital as well as across UCL to develop novel techniques to treat hypotony.

Hypotony is a condition caused by an imbalance between the production of fluid within the eye and outflow. In some patients, this imbalance starts to cause the eye to shrink leading to disorganisation of the structures within the eye.

To date, there are no treatments to reverse hypotony. Patients may have an operation to fill the eye with silicone oil, which stops the eye from shrinking further, but silicone oil has complications associated with long term use.

The treatment strategy, which is minimally invasive and low-cost, involves injecting a commonly used gel-like fluid into the vitreous cavity to slowly stretch the eye. Injections are administered in the retinal therapy unit and most patients require between 6-8 to restore the eye back to its original size.

Thus far, seven eyes have been treated and all patients have had significant visual improvement.

## Children's eye health tips

Good eyesight is crucial in ensuring that a child develops to their full potential. They may struggle to learn at school if they can't see clearly. We share information on how children's eyes develop, and advice from Moorfields for parents and carers to protect and improve their child's sight.

### How children's eyes develop

Children's eyesight develops rapidly as a baby. This visual learning process continues well into primary school age, up until around eight years old. After that, there is minimal ability for the vision to improve, so any eye problems must be detected and treated early.

### How do you know if a child has an eye problem?

Here are eight key things to look out for and consider:

1. An eye that drifts in or out
2. Frequent eye rubbing or blinking
3. Sitting very close to the TV
4. Headaches or eyestrain
5. Difficulty concentrating at school or problems reading
6. Family history of wearing glasses from a young age, childhood squints or eye diseases
7. Children with developmental conditions are more likely to have associated eye problems
8. More acute symptoms - red, sticky eyes suggest a bacterial infection. Red, itchy and watery eyes suggest an allergy. Severe light sensitivity can also indicate a problem.

**The only way to know that everything is ok is by having an eye test. You can find opticians on many high streets. This is recommended at least every two years for all children starting from three to four years old.**

The NHS fully funds eye tests for children under 16 years of age (and under 19 years in full-time education).

The good news is that children respond very well to treatment if an issue is picked up early. This might involve glasses or contact lenses, patching, eye drops, or sometimes surgery.



### What else can I do to care for my child's eyes?

- Encourage regular breaks from screen time to avoid eye strain
- Make sure their eyes are protected from the sun by wearing sunglasses
- Do not under any circumstances allow children to play with laser pointers
- Ensure they eat a healthy balanced diet, keep hydrated, and balance near focusing tasks such as reading and screen time with time playing outdoors.



**20% of school-aged children have an undetected vision problem.**

Our innovation grants create opportunities to push the boundaries. See our website for details [moorfieldseyecharity.org.uk/innovation-grants](https://moorfieldseyecharity.org.uk/innovation-grants) Open for applications in early 2024



For more information, visit the charity's website [moorfieldseyecharity.org.uk/news/looking-after-your-childrens-eyes](https://moorfieldseyecharity.org.uk/news/looking-after-your-childrens-eyes) Thank you to the optometry department at Moorfields for sharing your expertise.





## Chris' story – patient and para athlete

At just one month old, Chris Telesford found himself under Moorfields' care. A complex diagnosis shaped his life experiences. Starting at the tender age of three, Chris discovered his passion for Taekwondo and has been practising for nearly four decades. He is now an accomplished para athlete and coach.

### How did the diagnosis affect your life? How have you overcome challenges?

"My diagnosis revealed bilateral coloboma of the optic disc with nystagmus. Tasks like reading small print or recognising distant faces were difficult, but I kept them from defining my aspirations. I engaged in combat sports and other interests such as acting."

"I drew on my proactive spirit. Looking back at my initial days following the diagnosis – I was determined to face challenges head-on. Having a visual impairment in today's world may prevent you from flying a plane (to an extent), but the technology exists that allows you to still achieve your desired dreams and goals."

### How has Moorfields cared for you?

"I underwent swift laser surgery to address a retinal tear present since birth. Cataract treatments brought significant improvement. They enhanced my vision, allowing me to see the world with newfound sharpness.

The recent introduction of reading glasses has reminded me of life's natural changes that I welcome with open arms."

### What does Moorfields mean to you?

"Moorfields is more than a medical facility; it is a supportive community which has helped empower me. Minor hurdles occasionally emerged amid the triumphs, but the Moorfields team was always there to guide the way."

### What advice would you give to other people with sight loss?

"Trust the Moorfields consultants. Their expertise and dedication make them reliable guides on this unique journey. I never thought I'd be representing Great Britain at Taekwondo and pioneering ways to coach others with visual impairments. Taekwondo, for me, is not just a martial art or a way of keeping fit and healthy but is a way of life - coaching and instilling discipline, confidence, perseverance and integrity, and building an indomitable spirit."

**Chris' impact reaches beyond sports: he is a patient safety partner at Moorfields and is a member of the patient advisory board for Oriol – the new eye centre.**



## Our gifts in wills programme

Through August, September and October, you may have seen or heard about the NHS Charities Together gifts in wills campaign. The campaign message is 'leave a forever thank you in your will to an NHS charity'. In recent years, many people have been through life-changing experiences, and without the NHS, the outcomes might have been quite different. The campaign aims to provide an

opportunity to say 'thank you' to the NHS hospitals and staff for being there.

Moorfields Eye Charity joined the campaign with our message, which is 'make a will, you'll be making it so much easier for the people you leave behind'. We know that a will can help your loved ones by letting them know your wishes and what you want to happen when

you're not around.

We can help - Moorfields Eye Charity has two free will writing schemes, a face-to-face scheme, through The Goodwill Partnership and an online scheme through Bequeathed. Simple wills are provided free of charge, and if you'd like more details, please contact Jackie Birch, our legacy development manager.

**You can also get in touch with Jackie about any will-related questions, whether you have a will or are planning to make one – she's pleased to help.**

**For more information, contact Jackie Birch by email [jacqueline.birch1@nhs.net](mailto:jacqueline.birch1@nhs.net) or by calling 020 7521 4697**



Moorfields has been behind many of the most important developments in eye care over the last two centuries, and at Moorfields Eye Charity we exist to help ensure this continues. By entering our Christmas raffle you will be playing a direct role in the fight against sight loss, whilst also having the chance to win £5,000.

Enter our raffle and make a difference to the lives of people with sight loss, both today and in the future.

Please purchase as many tickets as you can and spread the word to your friends and family.



**Entering the raffle couldn't be easier, visit [mecraffle.org](http://mecraffle.org) and go to 'enter now' to win one of our fabulous prizes.**

Closing date is 8 December 2023

Draw takes place on 14 December 2023

After the draw, we'll contact you if you're one of our lucky winners and announce the winning tickets online.

For the raffle rules read [raffle.moorfieldseyecharity.org.uk/terms-conditions/](http://raffle.moorfieldseyecharity.org.uk/terms-conditions/)

# Enter our Christmas raffle today

1st

£5,000

prize

2nd

£750

prize

3rd

£125

prizes  
x10

By entering our Christmas raffle, you could win £5,000, at the same time as helping create a brighter future for those living with sight loss.

Moorfields and UCL are at the forefront of important developments in eye research and care, and we're proud to support their work. Last year, our raffle raised over £62,000 - we would love your help to make this total even greater for 2023. Whether it is used to fund the next research breakthrough for sight loss treatments, improve the experience of Moorfields' patients, or help educate the next generation of eye care specialists - your entry will make a massive difference.

## Previous winner

“Over the years, I've come to understand that Moorfields is a special place where many people have come from far and wide to receive treatment with wonderful results, not just myself.

It makes me incredibly proud that I have contributed to this by supporting Moorfields Eye Charity. It is my way of thanking Moorfields for what they've done for me.

When I found out I had won a prize in the raffle I thought “wow, that's amazing!”. I couldn't believe it, I've never won anything like it before so I was delighted. I shared some of the money with family and friends, but also treated myself! To anyone considering entering the raffle, I'd say have a go! It's a great cause. All people with eye conditions benefit from the work being done at Moorfields, and you could even be a winner like me!”

**Wendy Edmonds**  
Former Moorfields patient



Enter today at [mecraffle.org](https://mecraffle.org)



## How you can get involved

You can support us in many ways: set up a regular direct debit, leave a gift to us in your will, do your own fundraising, play the lottery, or donate to one of our seasonal appeals - these are just a few of them.

**Support children's eye health** - donate to our appeal to invest in research and change lives globally

**Lottery** - play our weekly lottery, win £25,000 and support Moorfields at the same time

**Fundraising event** - cycling, running or walking - we have lots of challenges to get you active

**DIY fundraising** - hold a cake sale, play a 24-hour game-athon - you can be as creative as you like!

**Regular giving** - support us with a regular gift and have an impact on the future of eye health

**Remember us in your will** - become part of our supporters' circle - the Moorfields Visionaries

**Winter appeal** - look out for this launching in November

**Eye to Eye** - hold the date: 23 June 2024, bookings open in January!

**Visit [moorfieldseyecharity.org.uk](https://moorfieldseyecharity.org.uk) for more details on the projects we fund**

### Get in touch

For further details: **Email:** [moorfields.eyecharity@nhs.net](mailto:moorfields.eyecharity@nhs.net) **Tel:** 020 7566 2565

### If you have a specific enquiry:

**Individual giving** - John Painter, [john.painter1@nhs.net](mailto:john.painter1@nhs.net) or 020 7566 2633

**Leaving a gift in your will** - Jackie Birch, [jacqueline.birch1@nhs.net](mailto:jacqueline.birch1@nhs.net) or 020 7521 4697

**Fundraising events** - Jo Green, [joanne.green28@nhs.net](mailto:joanne.green28@nhs.net) or 020 7521 4614

**Major giving, trusts and foundations** - Julide Troedson, [julide.troedson@nhs.net](mailto:julide.troedson@nhs.net) or 020 7521 4610

**Oriel fundraising campaign** - Rachel Jones, [rachel.jones310@nhs.net](mailto:rachel.jones310@nhs.net) or 020 7521 4610

**Research and grant-making programme** - Martin Cordiner, [martin.cordiner@nhs.net](mailto:martin.cordiner@nhs.net) or 020 7566 2565

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Registered Charity No 1140679 Registered No 7543237

Moorfields Eye Charity is a charitable company limited by guarantee and registered in England and Wales Registered office 162 City Road, London, EC1V 2PD

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