



LOOK FORWARD

ISSUE 187 AUTUMN 2025



Inside: The 'Running Retina Researchers' from the Ocular Cell and Gene Therapy Group, led by Professor Robin Ali and Professor Rachael Pearson at King's College London, ran the London 10K recently.

We are so grateful to everyone who has donated or raised money for Retina UK. There are lots of ways you can get involved in our anniversary year. The team will support you every step of the way. Find out more on pages 22-23.

Our 16 incredible #TeamRetinaUK trekkers will be taking on the Sahara desert in November. Their fundraising total currently stands at over £30,000! They are most definitely stepping out of their comfort zone and we'd like to wish them good luck and every success in this really awesome challenge.



Conferences are in the air

This edition of Look Forward brings news of some incredibly exciting research from Professor Rachael Pearson (pages 20-21) which is funded by Retina UK, thanks to your donations. We also have news about the latest gene therapy clinical trials (pages 6-7).

Events to mark our 50th anniversary year are now underway and this edition includes an interview with Elizabeth Baio who has been a part of Retina UK since the start of the charity. Elizabeth will be coming along to our Annual Conference in London on 20 September (pages 4-5) along with a large group of our volunteers. I look forward to seeing you all there. If you are able to, please get involved in our anniversary appeal or some community fundraising events. Your support is vital in allowing us to continue our much needed work.

I would like to end this update with some sad news. We heard in June that Professor Pete Coffey sadly passed away. His pioneering work in regenerative treatments for vision loss, including the landmark London Project to Cure Blindness, and his key studies demonstrating the potential of stem cell-derived therapies for age-related macular degeneration were pivotal in the search for treatments into inherited sight loss. I'd like to mark this significant loss to the research community and to offer our sincere condolences to his family and friends.



*Tina Garvey,
Chief Executive*

Look Forward is available as a hard copy, by email, audio (CD or USB) and in Braille. Get in touch if you'd like to receive a copy in one (or more) of these formats. If you no longer wish to receive Look Forward, please let us know by emailing **info@RetinaUK.org.uk**.

Retina UK is a charity searching for treatments and giving support every day, so everyone with inherited sight loss can live their best lives.

Retina UK, PO Box 350, Buckingham, MK18 1GZ

E: info@RetinaUK.org.uk · **T:** 01280 821334 (Office) · **T:** 0300 111 4000 (Helpline)

W: RetinaUK.org.uk · **E:** helpline@RetinaUK.org.uk

Together we can: Collaborating with Retina UK

SHEET ANCHOR EVOLVE

part of M Core



When the 14-year-old son of an employee of Sheet Anchor Evolve was recently diagnosed with retinitis pigmentosa (RP), they turned to Retina UK and an impactful and exciting new partnership was formed. Speaking about their decision to support our work, they said: “We wanted to help in any way we can towards advancing research and treatments for this condition.”

The company, which manages 98 properties, shops and shopping centres across the UK, will be supporting us in a variety of ways, including a charity walk, raffle, golf day, bake sale, company quizzes, collection boxes in its larger retail centres and vinyls on the front of its vacant shopping units with a QR code to donate.

On why they would encourage others to support Retina UK during our 50th anniversary year, the company said: “Retina UK is a great charity. Supporting them gives people living with inherited sight loss more opportunities. The charity have been very communicative throughout and

have offered a variety of different ideas. They have been a true partner and we are excited for the future.”

As well as partnering with Sheet Anchor Evolve, we are pleased to be working with other companies, including branches of Specsavers and Bupa, on exciting new collaborations throughout 2025 and 2026. These high-profile partnerships will enable us to raise much-needed awareness and funds.

If you would like to find out more about partnering with Retina UK, please email our Corporate Fundraising Manager, Chirag Mehta, on **fundraising@RetinaUK.org.uk** or call **01280 815900**.

Register now for our flagship conferences

There is still time to register for both our Annual Conference (Saturday 20 September) and our Professionals' Conference (Friday 19 September). Join us in person at the Holiday Inn, Regent's Park in London or online from the comfort of your own home.

Professionals' Conference – Friday 19 September

Our Professionals' Conference is suitable for all health, social care and education professionals. It is CPD accredited and is FREE to attend. This year's event will include specific sessions for ECLOs, rehabilitation and habilitation specialists and eye care professionals. Highlights include:

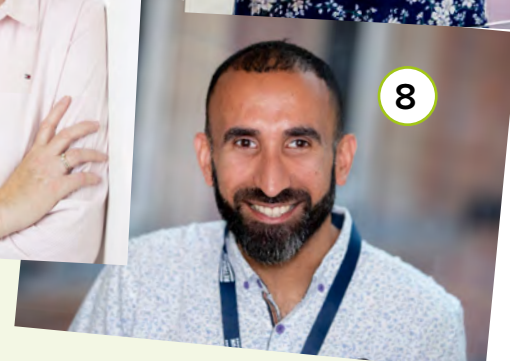
- From vision to reality: 50 years of progress (Kathy Evans, Chair of Trustees, Retina UK).
- Every experience counts: Insights from our Sight Loss Survey (Tina Garvey, Chief Executive, Retina UK).
- Learning from lived experience: In conversation with our community (Paula McGrath, Deputy Chief Executive, Retina UK, leads a panel session).
- Supporting the mental wellbeing of young people with inherited,

progressive vision impairment (Michael Crossland, Senior Research Fellow, University College London (UCL) Institute of Ophthalmology and Rachel Canavan, PhD student in Psychology, UCL).

Annual Conference – Saturday 20 September

Our Annual Conference 2025 marks the 50th anniversary of the charity. It is open to everyone, FREE to attend and is specifically aimed at those affected by inherited sight loss. Highlights include:

- From vision to reality: 50 years of progress (Kathy Evans, Chair of Trustees and Professor John Marshall MBE, Trustee, Retina UK).
- The journey so far: genes, machines, misses and marvels (Professor Michel Michaelides, Professor of Ophthalmology, University College London and Consultant Ophthalmic Surgeon, Moorfields Eye Hospital).
- Restoring the retina: a project at the cutting edge of treatment research (Professor Jane Sowden, Professor of Developmental Biology and Genetics University College London (UCL) Great Ormond Street Institute of Child Health).
- From bench to breakthrough: Biotech and inherited sight loss (speakers from Aavantgarde, Octant, Alkeus



Pharmaceuticals, Sepul Bio and Beacon Therapeutics).

- Iterative innovation and accessible technology (Christopher Patnoe, Head of EMEA Accessibility and Disability Innovation at Google).
- Together we thrive: Exploring new possibilities. Community members share their experiences on employment, sport and leisure, mobility and travel and day-to-day living.

In-person delegates can meet the day's speakers and visit the exhibition stands as part of an informal 'drop-in' session mid-afternoon. We have arranged an 'Ask the Expert' session for our online delegates, with Professor Julie Silvestri, Clinical Director for Ophthalmic Services at the Belfast Health & Social Care Trust, Honorary Professor at the

Some of our speakers:

- | | |
|-----------------------|--------------------|
| 1. Michael Crossland | 5. Louise Gow |
| 2. Bhavini Makwana | 6. Kathy Evans |
| 3. Christopher Patnoe | 7. Rachael Canavan |
| 4. Stevie Johnson | 8. Davinder Kullar |

Centre for Public Health at Queen's University Belfast and Co-Lead for the NI Clinical Research Network.

Join more than 300 delegates for our Professionals' Conference and more than 350 delegates for our Annual Conference. Visit our website to see the full programme and register to attend:

- RetinaUK.org.uk/annual-conference
- RetinaUK.org.uk/profs-conf

If you have any questions or if you would like to register over the phone, please call us on **01280 821334**.

Johnson & Johnson gene therapy – what happens now?

Johnson & Johnson's (J&J) experimental gene therapy for X-linked retinitis pigmentosa (RP) is currently under the microscope – but not in the way you might think! Despite previous positive findings causing excitement, progress has seemingly come to an abrupt halt, whilst we wait to hear the outcome of key decisions.

What is the therapy?

The new gene therapy, known as bota-vec, is for X-linked RP, associated with mutations in the RPGR gene.

It is a type of adeno-associated viral vector (AAV) gene therapy which means that a harmless virus is used to package and deliver a healthy version of the RPGR gene to photoreceptor cells. This gene will then enable the production of a functional copy of the RPGR protein. The results of the phase 1 and 2 clinical trials were encouraging, however, the phase 3 trial has reportedly failed to meet its primary endpoint.

What does this mean?

The conclusion about whether a treatment is effective is based on a clinical trial achieving a 'primary

endpoint'. This target is set before the trial begins and everything is planned around it. It is acknowledged that in rare conditions, trial endpoints can be difficult to design.

The primary endpoint of the LUMEOS phase 3 trial was an improvement in a 'vision-guided mobility assessment' (VGMA). This means that participants who received the gene therapy would need to show a significant improvement in navigating a maze in low light compared to their baseline attempt and participants in the control group.

Findings

The outcomes of the primary endpoint were described by J&J as 'directionally supportive,' but the result was not statistically significant, and the data was described as 'noisy' by researchers.

- The group that received the gene therapy experienced a 13.4% greater improvement on the VGMA test at one year compared to the control group.
- Multiple secondary endpoints showed clinically meaningful improvements – including a low luminance questionnaire (LLQ) of patient reported outcomes, multiple retinal sensitivity metrics and low luminance visual acuity.

- 45% of patients who received the gene therapy could read at least two more lines of letters on the eye chart compared with 7% of control group participants.
- 40% of patients showed meaningful improvement in at least 2 of the 3 domains (functional vision, retinal function, visual function); whilst 0% showed improvements in controls.

The LUMEOS clinical trial was widely reported by industry press to have failed, despite the positive findings. It now remains unclear where J&J will go from here, with no clear roadmap.

A J&J representative said:



“We’re working to understand the totality of the data, inclusive of the clinical relevance of improvement shown on the majority of secondary endpoints. We remain engaged with the advocacy and research community and greatly appreciate their continued support as we work to determine next steps.”

The concern over the suitability of endpoints in rare disease clinical trials is not a new phenomenon. It is commonly acknowledged that due to the rare nature of such conditions, trial endpoints are difficult to design and often lack suitability, which in turn can significantly affect promising new treatments. Like with many other clinical trials within the IRD space, the question left for J&J to answer from this data is whether this is a failed trial, or a failed treatment.

In other news, it is encouraging to see Beacon Therapeutics progressing through a phase 2 / 3 clinical trial for their laru-zova gene therapy for X-linked RP.

Preliminary trials have shown laru-zova to be generally safe and well-tolerated. The primary endpoint in the current trial is a 15-letter improvement from baseline in low luminance visual acuity. Early results could be available in mid-2026.

Whilst we acknowledge the frustration caused by the uncertainty in how treatments will move forward, it is encouraging to see positive preliminary results in a variety of clinical trials. We welcome an update from J&J as to how they plan to move forward and remain excited about the results from the Beacon Therapeutics trial. As always, we will update you in our regular newsletters and on social media. Sign up to our mailing list at: **RetinaUK.org.uk/get-involved/mailling-list/**.



Legal Support for you and your family


Everyone needs a lawyer at some time in their lives.

Our legal experts will support you with understanding and sensitivity. So whether you need help writing a Will, you've been in an accident, suffered an injury or illness that wasn't your fault, or you're looking at divorce options, we can offer clear guidance to get the right result for you.

Scan to
find out
more



We're proud to support Retina UK.

 0808 231 0508

 **irwinmitchell**

A lasting legacy

‘Make A Will Month’ in October is a great opportunity to take a moment to consider leaving a gift to Retina UK in your Will. Whatever the size, legacies have a huge impact and we are grateful to everyone who chooses to support us in this way.

Your contribution will ensure we can be here for the ever-increasing number of people, and their families, who are affected by inherited sight loss and turn to us for support. Your gift could also fund ground-breaking discoveries in the rapidly changing field of research, leading to the development of treatments for inherited retinal conditions in the future.

Colin McArthur has included a gift to Retina UK in his Will: “I always hoped that my sight would be restored in my lifetime. None of us know what the future holds, and it is vital that research and support is continued. My ultimate hope is that inherited sight loss is eradicated.”

Colin also shares his hopes for the future: “My children and grandchildren will benefit if a treatment is found in the future, even if it is not available in my lifetime.”



To find out more about writing a free Will, please visit our website: **RetinaUK.org.uk/legacy**.



To discuss leaving a gift to Retina UK, please call our Head of Income Generation, James Clarke, on 07736 925174 or email **james.clarke@RetinaUK.org.uk**.

Volunteer spotlight: Elizabeth Baio

Elizabeth first heard about Retina UK (then the British Retinitis Pigmentosa Society) when our founder, Lynda Cantor MBE, spoke on BBC In Touch in early 1977. She went along to the charity's AGM the same year and stayed in touch with Mary Guest, one of the speakers. Mary later invited her to join what became the National Welfare Committee along with the late Bob Gould and Stephen Goulden, who continues to volunteer for the charity to this day. Together they helped to set up the charity's Helpline in the 1980s. When she retired after a career as a social worker in 2008, Elizabeth started volunteering on our telephone Helpline.

Elizabeth is living with retinitis pigmentosa (RP), she tells us: "I never had good vision and I couldn't understand why other people could see in the dark because I wasn't able to. I lost my central vision first and remember asking my father 'when you look at Mummy, do you see her all at once'? The consultant told my mum that my condition was rare, that I wouldn't be able to work and to just take me home!" There is no family history she is aware of and her own children and grandchildren are unaffected.



Elizabeth first experienced visual hallucinations, known as Charles Bonnet Syndrome (CBS) at the age of 13. She said “I was a teenager in the psychedelic 1960s, and people were taking and describing all sorts of hallucinogens. I had no knowledge of drugs at all and had never taken anything but felt I couldn’t say I was seeing things that weren’t there!



“I first heard about CBS in my 30s at work. One of my colleagues asked me if I had heard of something called Charles Bonnet Syndrome? She told me about a visually impaired lady who ‘keeps talking about these images that are just not there’ so we looked it up in the medical dictionary. I did meet one lady who had been sectioned under the Mental Health Act because she said there was a crowd of people in old fashioned dress with pitchforks walking up the street. That’s not uncommon.”

“Judith Potts from Esme’s Umbrella spoke at a Retina UK volunteer training weekend and at the end of her session, she asked if anyone had personal experience of CBS. It was then that I spoke about mine for the very first time.

“I met Dominic Fitch, an expert in this field, and attended several conferences about it. For a while, I took quite a few calls from the RNIB helpline about CBS. It grew because I’m interested and because so many people don’t talk about it. Bottling things up never helps.”

When asked about the future of the charity, 50 years on from its formation, she said: “My hope is that progress will be made in research. I’m aware they’re probably not going to be miraculous for most, but anything that can prolong useful vision would help. I also hope there is still support for people to have a good quality of life. Sharing fears and problems with someone with similar experience can be the first step towards finding your own way forward. Some people still don’t know about peer support groups, how useful it is to talk to others and how it can dispel some of the fear, loneliness and isolation they may feel.” You can learn more about Retina UK Peer Support Groups on pages 14-15.

If you are interested in volunteering with Retina UK, we are arranging bucket collections and information stands at theatres around the UK for Chris McCausland’s “Yonks!” tour. If you would like to get involved, please email fundraising@RetinaUK.org.uk or call 01280 815900.

Show your support in our 50th anniversary year

During our 50th anniversary year, we need your support more than ever.

Since we were formed five decades ago, we have invested over **£18 million** in ground-breaking research into inherited sight loss and although we have made progress, our vital work is far from done. Approximately 25,000 people in the UK are living with an inherited sight loss condition and Retina UK will always be the voice of the community while funding the search for future treatments.

We continue to support innovative research projects in areas such as gene therapy and photoreceptor stem cell patches, at institutions like UCL, Kings College London, Edinburgh University and Newcastle University – all because of you! In our 50th year, we need to maintain momentum and accelerate the search for treatments, but we can only do this with your continued support.





Registered with
**FUNDRAISING
REGULATOR**

To donate today and contribute to our vital work:

- Call 01280 815900 (Monday – Friday, 9:00am – 5:00pm)
- Donate online via **RetinaUK.org.uk/appeal**



- Text ANNIVERSARY to 70560 to donate £10 (donations will cost £10 plus one standard network rate message)
- Send a cheque to Freepost Retina UK. Please write your full name, address and '50th anniversary appeal' on the back.

Double your donation

to our anniversary appeal from **2–9 December** by making a gift through the Big Give Christmas Challenge match funding campaign. Our target in 2025 is an ambitious £100,000, the highest ever!

More information about the Big Give Christmas Challenge will be shared in the next edition of Look Forward.

Thank you for supporting our vital work for 50 years and counting.



“The research funded by Retina UK has been an important way for me to cope with my diagnosis. It gives me hope not just for myself, but for future generations that they are advancing ground-breaking medical research.”

Krishna

BBC Lifeline appeal - save the date

We are absolutely thrilled to announce that Retina UK will be the focus of a BBC Lifeline Appeal on **Sunday 16 November**.

Please save the date, tune in and share the news with your friends and family. It is a terrific opportunity to raise awareness of inherited sight loss conditions like retinitis pigmentosa (RP) as well as to raise much needed funds.

We will reveal the face of our appeal on social media and in our e-newsletter nearer the time!

Dates for your diary

Our anniversary year is now underway with our Conferences just a few weeks away.

Details of all of our events can be found on our website RetinaUK.org.uk/events. You can also call our office for more information 01280 821334.

SEPTEMBER

Great North Run (7 September)

The Big Half (7 September)

Edinburgh Local Peer Support Group (13 September)

QAC Sight Village: Blackpool (16 September)

Retina UK Professionals' Conference (19 September) - London

Retina UK Annual Conference (20 September) – London

Raffle draw (20 September) – London

Dorset & South West Local Peer Support Group (23 September)

'Talking' Tech Peer Support Group (25 September)

Lake District Eight Peaks Challenge (27 September)

Robin Hood Half Marathon (28 September)

OCTOBER

Great Scottish Run 10K and Half Marathon (5 October)

Cardiff Half Marathon (5 October)

National Peer Support Group (9 October)

Retina UK Day 2025 (9 October)

Royal Parks Half Marathon (12 October)

Tyne & Wear / Northern Alliance Local Peer Support Group (18 October)

Welsh Three Peak Challenge (24-26 October)

NOVEMBER

Look Forward winter 2025 edition

Sahara Desert Trek 2025 (6-11 November)

BBC Lifeline appeal (16 November)

QAC Sight Village: London (18-19 November)

'Talking' Tech Peer Support Group (20 November)

DECEMBER

Big Give Christmas Challenge 2025 (2-9 December)

MARCH 2026

Paris Half Marathon (8 March)

JUNE 2026

Retina UK Gala Dinner (6 June)

APRIL 2026

Paris Marathon (12 April)

London Landmarks Half Marathon (12 April)

Adidas Manchester Marathon (19 April)

TCS London Marathon (26 April)

Dates are subject to change. Please check our website for up-to-date information:

- Peer support groups: RetinaUK.org.uk/groups
- Webinars: RetinaUK.org.uk/webinars
- Challenge events: RetinaUK.org.uk/challenge

MAY 2026

5K a day in May

The power of making connections

Our peer support groups provide a fantastic opportunity to meet other people living with similar conditions. Our community regularly tell us how much they value the chance to connect:

“Everyone is always so welcoming and inclusive. It’s a great place to feel you are not alone. Guest speakers have always been very relevant and interesting. I’m excited about the launch of a peer support group covering my area and look forward to becoming part of that community.”

Dorset & South West Peer Support Group member.

“Absolutely love our meet ups with the lovely friends I have made through Retina UK”

London & South East Peer Support Group member.

“It’s always good being amongst our group members and listening to their problems and successes in life. I always look forward and enjoy our meetings. Being with like-minded people gives me so much confidence.”

‘Talking’ Travel Peer Support Group member.

“Our peer support group meetings are so friendly and helpful too. Any questions you have are answered by at least one person in the group no matter how silly they may seem. I would be lost if ever they stopped. Well done Retina UK and thank you.”

‘Talking’ Travel Peer Support Group member



Audio Described Performances with Northern Ballet

Did you know that Northern Ballet, the UK's foremost narrative ballet company, audio describe their performances for blind and visually impaired people?

Co-written by former Premier Dancer Pippa Moore MBE and VocalEyes, our audio descriptions bring our performances to life. You will hear descriptions of the movement, the action and the drama happening onstage.

Audio Description ticket holders are also invited to a live Touch Tour Insight Workshop, where you can hear about the scenery, feel the props and costumes, and discover the shapes and quality of the movement from the ballet with the help of Company dancers.

Upcoming Audio Described performances:

Merlin

Touring Autumn 2025:

Leeds, Nottingham, Sheffield & Norwich

Little Red Riding Hood

A ballet for children touring Autumn 2025 – Spring 2026:

Leeds, London & more

The Nutcracker

January 2026:

Leeds

Gentleman Jack

Touring Spring 2026:

Leeds, Sheffield, Nottingham, London, Norwich, Salford & Bradford

Find out more at northernballet.com/audio-described-performances or contact info@northernballet.com

Northern Ballet Audio Descriptions supported by



Supported using public funding by
**ARTS COUNCIL
ENGLAND**



**THE POWELL FAMILY
FOUNDATION**

Kevin Poeung and Ashley Dixon in Merlin. Photo Emma Kauldhar. All information is correct at the time of publishing. Northern Ballet reserves the right to make changes without prior notice. Northern Ballet registered charity number: 259140. Company registration number: 947096. VAT number 202 0374 70.

As the UK's leading provider of hardware and software to the blind, visually impaired and those with learning and reading difficulties, our products can improve your quality of life at work, at study or at home.



SmartVision 3 Mobile Phone

Hearing aid compatibility



Voice command and recognition



Localised GPS navigation



Optical character recognition



Touch screen and keypad



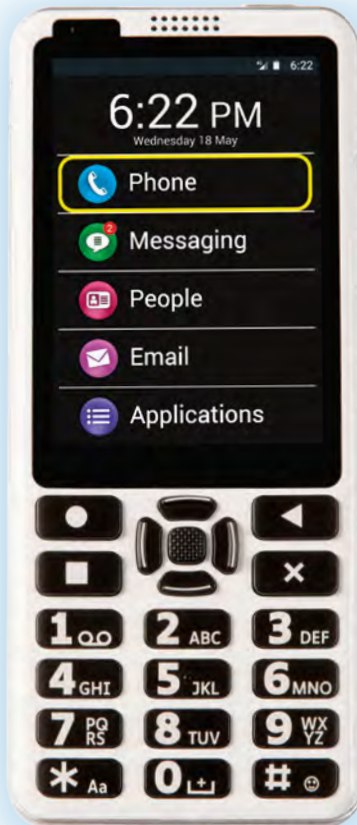
Vocalised user interface



Multi-format audio playback



Magnifier with filters



SmartVision 3 Omni £760

- Smartphone
- USB-C cable
- Stereo headphones
- NFC tags (x5)
- SIM extraction tool
- Inductive charger
- Protective case
- Neck Strap
- Protective glass
- Cleaning cloth
- KAPTEN pedestrian GPS
- Book & document reader

SmartVision 3 Initium £542.50

- Smartphone
- USB-C cable
- Stereo headphones
- NFC tags (x5)
- SIM extraction tool

If you prefer a simple, talking, big button mobile phone without smart features, check out the **MiniVision2+** on our website!

Other solutions we have include WeWALK Cane, Envision Glasses, OrCam, desk & portable electronic Magnifiers.



Online
www.sightandsound.co.uk



Call
0800 085 6055

Contact us for more information

THANK YOU

#TeamRetinaUK

Whatever you do to support Retina UK, from organising a bake sale to taking on an epic challenge, it is hugely appreciated by us all. We are pleased to shine a light on some of our fantastic supporters in our Thanks To You pages. We quite simply can't do it without you.

In May, lots of wonderful Retina UK supporters took on 5K A Day In May and raised over **£7,500** for our vital work. From walking to cycling, they completed their 5K of exercise in the sunshine and raised awareness and funds at the same time.



Pam Bickle and the wonderful Ladybirds Song Group raised **£511** by choosing us as their chosen charity for their performances throughout June.



In July, Ben Ramus rounded up 11 friends to take on the National Three Peaks. Through their epic 24-hour challenge, the team raised a staggering **£3,138** for Retina UK.



This summer, long-term supporter, Bhavini Makwana, organised a group challenge to climb the O2 Arena. They raised £600 through their daring efforts!

Thank you to everyone who has fundraised for Retina UK over the last few months.



Lucy McFarlane and her colleagues at Blackwood School took on the Royal Sutton Fun Run in Birmingham in June and raised an amazing **£834!**



In April, Robin Frape and Julie Binnington took to their kayak on the Isle of Wight and completed an epic challenge for us, raising a fantastic **£852** in the process!

As part of their fundraising for the Sahara Desert challenge in November, the Sanford family organised a family fun day at Enchanted Wood Preschool in Bexleyheath and raised a huge **£10,000!**



Long-term supporter, Jane Sellers, kindly raised and donated **£200** from a church talk and collection in Surrey. We are so grateful for Jane's continued support.

Sally Thomas organised a quiz night in Cheltenham in May and raised **£730** for Retina UK through her fantastic community event.



Lynn Coates ran the Manchester 10K in May and raised an amazing **£510** through her inspiring efforts as part of #TeamRetinaUK.

If you would like to get involved, we'd love to hear from you. Call James on 07736 925174 or email james.clarke@RetinaUK.org.uk. Details of all of our upcoming challenge events can be found on our website: RetinaUK.org.uk/challenge.

Please share your photos with us at fundraising@RetinaUK.org.uk or tag us on social media.

Vision in a dish: How retinal organoids could accelerate the search for a cure

In recent years, scientists have harnessed the remarkable power of stem cells to produce retinal organoids – tiny, three-dimensional ‘mini retinas’ grown in the lab.



Professor Rachael Pearson

The stem cells can be generated from adult skin cells, including those from individuals with inherited sight loss, meaning that the resulting organoids are hugely powerful living models of human retinal degeneration. They allow scientists to better understand disease mechanisms and test potential treatments, playing a vital role in accelerating research.

Professor Rachael Pearson and Professor Robin Ali lead the Ocular Cell and Gene Therapy group at the Centre for Gene Therapy & Restorative Medicine at King's College London. With the support of Retina UK, Professor Pearson is engineering important improvements to retinal organoids so that they can provide an even more accurate representation of the human retina. Her team is also developing organoids to provide a source of photoreceptors for future transplantation treatments.

“Creating retinal organoids is a bit like cooking” Professor Pearson tells us. “You need to have the recipe, but

if you give the stem cells the right signals in the right order, they follow what happens in normal development remarkably accurately.”

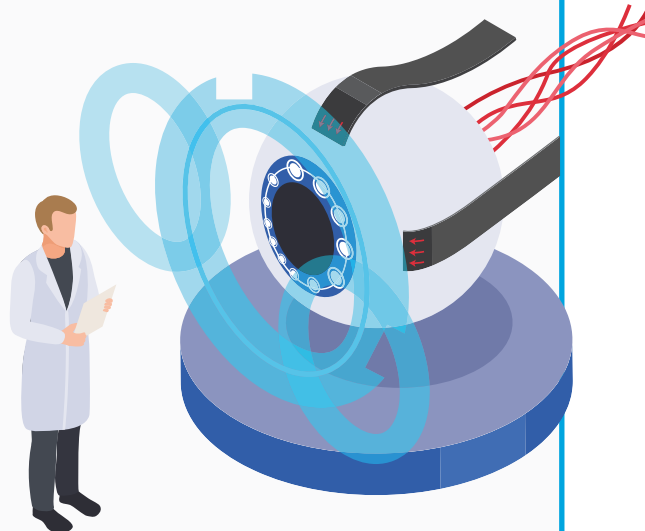
Scientists have learned how to tweak the recipe depending on how the organoids will be used; for example, Professor Pearson can create organoids with ramped up photoreceptor production to supply the team's transplantation research. But accurate disease modelling, which requires the organoids to remain healthy for extended periods, comes with some challenges.

“Photoreceptors mature quite late and by the time they do, the retinal ganglion cells (RGCs), which are located inside the organoid, start to die off” she explains. “This is likely because they run out of nutrients and because their axons, which usually form the optic nerve, have no exit from the organoid. Another limitation is that organoids have little retinal pigment epithelium (RPE), which is needed for photoreceptors to function properly.”

The retina explained

The retina is made up of multiple layers which include:

- The retinal pigment epithelium (RPE) which nourishes and supports the adjacent photoreceptors.
- Photoreceptors, which sense light and generate an electrical signal in response.
- Retinal ganglion cells (RGC), which relay signals from the photoreceptors to the optic nerve.



Professor Pearson will use funding from Retina UK to address these issues via some ingenious engineering: “We are using biomaterials to create a scaffold that encourages the RGCs to send their axons out of the organoids to form an optic nerve bundle. This recapitulates what happens in normal development, and we expect it to improve organoid organisation and survival.”

Robust organoid models are an essential tool to allow scientists to study human disease in human tissue. She said: “Animal models are vital, but there are differences, and this can sometimes affect the way treatments work. Having both in our toolkit greatly increases the chances of developing effective therapies.”

Therapies for advanced retinal disease might include the use of the organoid-derived photoreceptors themselves. The King’s College team uses organoids to provide cone photoreceptors that can be purified and banked for transplant. “We

now have extensive data showing that transplantation of these human photoreceptor cells into mouse models of advanced retinal degeneration, results in improved visual function and we are aiming to start a clinical trial in 2027” she tells us.

Retina UK is currently funding two other projects ultimately aiming at photoreceptor transplantation: Professor Majlinda Lako is developing stem cell-generated photoreceptors that will be “invisible” to the recipient’s immune system, while Professor Jane Sowden (who will be speaking at our Annual Conference on 20 September) is developing a tiny scaffold structure in which the photoreceptors can be embedded for transplant.

We are very grateful to all of our supporters for enabling us to fund this exciting work. In particular we would like to thank the Stavros Niarchos Foundation (SNF) for their contribution to Professor Pearson’s project.

Organise a fantastic fundraiser this autumn!

This autumn, there's plenty of ways you can support us and we will be here to help you every step of the way. From fundraising top tips to branded materials, we would love to hear from you with your exciting ideas during our 50th anniversary year. Please email **fundraising@RetinaUK.org.uk** or call us on 01280 815900.



“Organising an event for Retina UK and contributing to their research projects was such a positive experience. To see the difference the fundraising made was very rewarding and the support I received from the charity from start to finish was incredible. I will definitely be doing more fundraising.”

Alexandra, who organised a charity Christmas concert in 2024.



Get your bake on

Could your workplace, school or local community venue host a bake sale at Halloween or on Bonfire Night? Enjoying yummy treats and contributing to our worthwhile cause is a great way to bring people together, raise money and feel good (and full!).

Round up items for your own raffle

Organise a raffle in your hometown and ask local companies to donate prizes. It's a lovely way to show your support for Retina UK and selling raffle tickets in your community gives your loved ones the opportunity to win big whilst supporting us at the same time.

Organise a quiz night

A quiz night is a quick and easy way to raise vital funds for us and it's a great way to bring people together, complete with friendly rivalry! Whether you need help with your questions or you would like some branded items to decorate your venue with, we are here to help you bring your quiz night ideas to life!



Donate your stamps

Why not ask your friends and neighbours to collect stamps? It's an easy way to get involved and support us.

If possible, cut the stamps out, leaving 5-10 mm of envelope and post them to 'FREEPOST Retina UK'. To keep appeal costs as low as possible, please only use FREEPOST once you have collected approximately 200g of stamps.

If you have a smaller quantity of stamps and would like to send them, please pop them in a stamped envelope to Retina UK, Whiteleaf Business Centre, 11 Little Balmer, Buckingham, MK18 1TF.

Support us as you do your online Christmas shopping

It may only be September, but many of you will be planning ahead for Christmas. The 'Give As You Live' scheme is a great way to earn donations for Retina UK as you do your online shopping! Big stores including eBay, Marks and Spencer, Argos, Tesco, Sainsbury's, Trainline, Waitrose, Boots and thousands more are part of the scheme. Visit **giveasyoulive.com** or scan the QR code below to find out more and support Retina UK – simply by shopping online.



Spread cheer and raise funds!

Spread some festive cheer with our stunning Christmas cards. To avoid disappointment, we recommend stocking up sooner rather than later.

With four fantastic cards to choose from, including two that were designed by members of our community, you can support Retina UK whilst spreading some goodwill. You will not only be sharing the joy of the season, but also directly supporting people affected by inherited sight loss.

To purchase a pack, please visit **RetinaUK.org.uk/shop** or call 01280 815900 to order yours today.



Bag yourself a bargain in our shop sale!

Are you a bargain hunter? Do you want to feel good as you place your charity shop order?

We are pleased to share that our online shop continues to grow. If you are looking for a t-shirt, cap, mug, notebook, water bottle, pen or

something else, our online shop is the place to be.

To browse our ever-growing range, please visit **RetinaUK.org.uk/shop** or call 01280 815900 to place your order over the phone.

