# Look Forward, ISSUE 186 – SUMMER 2025

This edition marks the start of our 50th anniversary year. In April 1975 our founder, Lynda Cantor MBE, held the very first committee meeting for the British Retinitis Pigmentosa Society (BRPS). The organisation was registered with the charity commission on 6 June 1976. BRPS became RP Fighting Blindness in 2013 and Retina UK in 2018.

WE WOULD LIKE TO SAY A HUGE THANK YOU to everyone who has been part of the charity over the past 50 years. We have come such a long way and we are looking to the future with hope and positivity.

## Help us to mark our 50th anniversary (Tina Garvey)

Welcome to our summer 2025 edition of Look Forward and the start of our 50th anniversary year. We want to hear all your Retina UK stories, so please share your memories of the charity with us (or your thanks) by calling our 50th anniversary message line on 01280 733190 or sending your recorded audio or video message on WhatsApp to 07719 967368. If you'd prefer to send something written, please email [communications@RetinaUK.org.uk](mailto:communications@RetinaUK.org.uk).

A huge congratulations to the 28 #TeamRetinaUK runners in the [TCS London Marathon](#_CP_Track_11:). Between them they have raised more than £65,000. Thank you to them, their friends, family and colleagues for all their support. It is an incredible achievement. We hope they soaked up the fantastic atmosphere and that their recovery was swift.

We have an exciting line-up planned for our Conferences which take place on 19 and 20 September in London. If you can, please come and meet the team and community in-person. If you can’t join us in London, please register to attend online.

This month sees the start of our ambitious 50th anniversary appeal, which aims to raise £250,000 over the next 12 months. It will help us do what we do best - funding research and providing information and support for you and your family. There are lots of ways you can get involved, visit [Support our anniversary appeal](#_HJ_Track_9:) and [Get involved in our anniversary year](#_HJ_Track_10:) for more information.

Thank you to everyone who completed our Sight Loss Survey 2025. We are reviewing the findings to understand how we can make the biggest difference and will report back on the findings in the next edition of Look Forward.

Finally, thank you to all of our volunteers, including our leaders, the Trustees, who generously give their time and expertise to support the work of the charity. I have said it many times before, but we simply couldn’t do what we do without them. The charity was formed and run by volunteers 50 years ago and they continue to be at the heart of everything that we do.

See you in London in September.

## Win up to £1,000 cash in our annual raffle

Do you want to be in with the chance of winning up to £1,000 whilst also supporting those with inherited sight loss? Our raffle is back by popular demand.

For your chance to win one of five spectacular prizes, including the top prize of £1,000, a state-of-the art electronic magnifier worth more than £2,000 and Chelsea FC signed memorabilia, take part this summer.

Traditional print raffle tickets will be available from 1 July but you can take part online NOW by visiting [**RetinaUK.org.uk/raffle**](https://retinauk.org.uk/get-involved/fundraising/raffle/).

If you would like to pre-order traditional raffle books or have a query, please get in touch by emailing [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk)or call us on 01280 815900.

Tickets are just £1 each and your generous support will go towards helping us to advance our innovative research projects and maintain our vital services, allowing us to support those who are living with inherited sight loss – both now and in the future.

Adrian Paternoster spoke about how he was supported:

“I was diagnosed with retinitis pigmentosa not long after I got married. It really took a toll on my mental health, and I was struggling as my vision deteriorated – it was affecting so many aspects of life, including work, and my hobby of making art. I called the Helpline, and I can honestly say that call saved my life. The Retina UK community feels like a family to me. My confidence has definitely grown.”

The draw will take place on 20 September 2025 at our Annual Conference in London. We will be in touch to let you know if you are one of our lucky winners.

Thank you for your fantastic, continued support and good luck!

## Register now for our flagship event of the year

**When**: Saturday 20 September 2025

**Where**: Holiday Inn, Regent’s Park, London (W1W 5EE)

**Register**: [RetinaUK.org.uk/annual-conference](https://retinauk.org.uk/event/annual-conference/) or phone 01280 821334

**Cost**: Free to attend

Our Annual Conference is an excellent opportunity to find out the latest news from Retina UK, hear from expert speakers, meet other members of our community and to make new connections.

We are back in London in 2025 to mark the 50th anniversary of the charity and to look ahead to the future.

New for 2025! In-person delegates can meet the speakers in an informal setting at the end of the day.

The line-up is as follows:

**9:30am** Registration, networking, exhibition stands.

**10.00am** Welcome and housekeeping.

**10.05am** From vision to reality: 50 years of progress (Kathy Evans, Chair of Trustees, Retina UK).

**10.25am** 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).

**10.45am** Restoring the retina: a project at the cutting edge of treatment research (Professor Jane Sowden, Professor of Developmental Biology and Genetics at University College London (UCL) Great Ormond Street Institute of Child Health).

**11.15am** Break

**11.45am** From bench to breakthrough: Biotech and inherited sight loss (speakers from Aavantgarde, Octant, Alkeus Pharmaceuticals, Sepul Bio and Beacon Therapeutics).

**12.15pm** Iterative innovation and accessible technology (Christopher Patnoe, Head of EMEA Accessibility and Disability Innovation at Google).

**12:45pm** Lunch

**1.35pm** Creating change together (James Clarke, Head of Income Generation, Retina UK).

**1.55pm** Together we thrive: Exploring new possibilities (community members share their experiences):

• Employment

• Sport and leisure

• Mobility and travel

• Day to day living

**3.00pm** Your questions answered: Meet today’s speakers.\*

**4.00 pm** Close

All sessions are subject to change.

\*In-person delegates only.

Aged 18 to 30? We are offering support with reasonable expenses for a limited number of young adults with inherited sight loss to attend the Conference. Tick the box on the online registration form and we will be in touch with more information.

**QUOTE** from Alison, a 2024 Annual Conference attendee:

“This was the first event I have attended about sight loss and since I started losing my sight. I came on my own and it was very daunting. I have nothing but praise and thanks for all the staff and volunteers who made the conference happen. I was met at the station and made to feel so welcome and comfortable and was looked after all day. I can’t thank you all enough. I have hopefully made some good contacts and now have the confidence to join in other events. I don’t feel so alone now. Honestly, attending was the best thing I could have done. Thank you all.”

## Looking for clarity with genetic testing

Rob Sears, a human performance specialist and content creator living with inherited sight loss, recently underwent genetic testing at Moorfields Eye Hospital.

Through his YouTube channel, Blind Focus with Rob Sears ([@BlindFocusRS](https://www.youtube.com/@BlindFocusRS)), he hopes to empower others facing similar challenges. Having always lived with the knowledge that X-linked retinitis pigmentosa (RP) runs in his family, Rob had never questioned his diagnosis.

Rob spoke to his GP about getting a referral for genetic testing at Moorfields because his mum and grandad were previously seen there. Prior to genetic testing, the usual retinal examinations were completed by an ophthalmologist and his family history was discussed.

Rob’s results were then reviewed by a professor, who suspected that he may not have X-linked RP at all, but rather a different retinal condition, Choroideremia. He explained that RP and Choroideremia share lots of similarities in symptoms and presentation, highlighting the importance of genetic testing.

“Being 43, and somebody saying, actually what you’ve been told all the way through your life, I’m not sure that’s correct, was hard,” said Rob.

With no record of genetic testing in the family prior to Rob’s visit, whole genome sequencing (WGS) was the most suitable option. WGS results can take up to a year and waiting that long for answers can be difficult, but Rob’s experience as a para-triathlete has helped him to remain focused on the bigger picture.

Rob is hopeful that the results from WGS will provide clarity about his condition, for both him and his parents, and raise awareness around the importance of genetic testing.

Rob explained: “The point of this story is more poignant since I avoided testing because I thought I knew what I had.

“Don’t be afraid to go and do it. It’s massively important.”

Sian Sperring, an ophthalmology genetic counsellor at Oxford Eye Hospital, answers a few of the most frequently asked questions around genetic testing.

### Will I have to pay and who do I ask?

In the UK, genetic testing is freely available on the NHS when arranged by a specialist doctor. Speak to your GP or ophthalmologist who can make the appropriate referrals.

### Will they definitely find the causative gene?

For 25 – 30% of people living with an inherited retinal condition, a genetic test will fail to return a result. However, even if this is the case, your clinical diagnosis still stands. It is possible that small changes in the DNA code, called a variant of uncertain significance will be detected. This occurs when a genetic change is found but not yet fully understood.

### I would not be interested in receiving any kind of therapy or treatment. Is it still worth me getting a test?

From understanding how your condition will progress, confirming your family’s inheritance pattern and opening choices for you and close relatives, there are many reasons why genetic testing is beneficial. It can also help you to access the right support from organisations like Retina UK and connect with others going through similar experiences. Speaking to a genetic counsellor can help you to make an informed decision.

More information on why genes matter can be found at [RetinaUK.org.uk/genetics](https://retinauk.org.uk/genetics/).

## Our 2024 in numbers

* £1.6 million Total charitable spend
* £720K Invested in medical research
* £740K Committed to ongoing research projects
* 11 Research projects supported
* 1,218 New people began accessing our information and support
* £575K Spent on providing information and support
* 633 Helpline calls and 282 emails responded to
* We are in touch with 9,058 people affected by inherited sight loss
* 66 people registered onto our Discover Wellbeing portal
* 1,206 People registered for our peer support group meetings
  + 23 active groups, including three new local groups and two new online groups
  + 85 peer support group meetings
  + 17 physical locations, one national and five special interest groups
* 17 active volunteers supporting 35 service users on our Talk and Support service
* 2,923 Podcast listens on our podcast channel on Spotify
* Seven Lived experience panel participation opportunities
* 75% increase in subscribers to our YouTube channel +547% of views
* 6,473 Facebook support group members
* 22,869 Copies of Look Forward shared
* 33,358 Copies of our e-Newsletter shared

You can read the full Impact Report 2024 at [RetinaUK.org.uk/resource/impact-report-2024](https://retinauk.org.uk/resource/impact-report-2024).

## How genetic testing can support research

One of the reasons that people consider getting a genetic test is so that they might more easily be able to participate in research studies.

Researchers often want to recruit participants whose sight loss is caused by a particular gene. This might be for a clinical trial of a new treatment, but equally important are those studies that aim to create a more accurate picture of symptoms and progression or understand more about the condition’s impact on everyday life. All these types of studies contribute to bringing treatments and better care to the NHS.

Some studies, particularly clinical trials, have strict guidelines about who can take part. Criteria for inclusion or exclusion from the trial usually include factors such as age, stage of disease, and gene mutation. These criteria are essential to ensure that the trial produces meaningful results and to help maintain participant safety.

### How can I find out about taking part in studies?

Some hospitals keep their own databases of patients who are particularly keen to contribute to research – check with your ophthalmologist to see if they have one. Alternatively, you can explore the following:

* The research arm of the NHS, the National Institute for Health & Care Research (NIHR) website ‘Be Part Of Research’ allows you to search for UK-based studies on your condition. Visit [BePartOfResearch.nihr.ac.uk](https://bepartofresearch.nihr.ac.uk/). You can also register for alerts.
* Moorfields Eye Hospital in London and Oxford Eye Hospital research databases (open to all). Researchers use the database to look for appropriate participants for studies. Visit [research.moorfields.nhs.uk](https://research.moorfields.nhs.uk/)(Moorfields) [EyeResearchOxford.org.uk/research-register](https://www.eyeresearchoxford.org.uk/research-register)(Oxford).
* The Retina UK Lived Experience Panel. Opportunities range from research questionnaires to occasional clinical studies. To register, visit [RetinaUK.org.uk/more-info](https://retinauk.org.uk/get-involved/lived-experience/)or call us on 01280 821334. Please note that we may not be made aware of every clinical trial that’s happening in the UK.
* The US National Institute of Health website [clinicaltrials.gov](https://www.clinicaltrials.gov/)includes information about clinical studies across the world. However, this website is not regulated. If you are considering joining a trial found on this site, always discuss it with your ophthalmologist or doctor to ensure it is legitimate. Participation in a genuine clinical trial will never require payment.

## Annual General Meeting notice

Our AGM will take place on Wednesday 30 July 2025 at 7.15pm online (Zoom), to allow as many of our members as possible to take part.

Online, postal and telephone voting will be held in advance of the AGM, meaning all members who choose to do so can exercise their right to vote at a time, and in a format, that is accessible to them. **All members with voting rights will receive information on how to vote.**

We will present the results of the vote at our online interactive AGM meeting. All are welcome to attend the meeting where there will also be the opportunity to hear from our Chair and Treasurer and to ask them, the Board and our Chief Executive questions. Details of how to join the AGM can be found at [RetinaUK.org.uk/news/agm-2025](https://retinauk.org.uk/news/agm-2025).

### Agenda

1. Welcome
2. 50 years of making a difference: Marking Retina UK’s 50th Anniversary
3. Apologies
4. Approval of the minutes of the previous AGM (result of online voting)
5. Presentation of the annual report and accounts for the year ended 31 December 2024
6. Adoption of the Annual Report and Accounts for 2024 (result of online voting)
7. The appointment of the auditors (result of online voting)
8. The appointment of trustees (result of online voting)
9. Presentation of Retina UK activity in 2024 and 2025 plans
10. Any other business

## Support our anniversary appeal

In our 50th anniversary year, we’re asking you to join forces with Retina UK so that together we can foster hope for a happier tomorrow for the thousands of people across the UK who are living with inherited sight loss. Your generous donations have enabled us to fund the very best, ground-breaking research projects and be a trusted support network for the inherited sight loss community for 50 years! Please help us continue our mission in the future.

By supporting us today, you will be helping to fund exceptional scientists who are leading important translational medical research. At Retina UK, we are supporting innovative research projects in areas such as gene therapy and photoreceptor stem cell patches, at institutions like University College London (UCL), Kings College, Edinburgh University and Newcastle University – and this is only possible because of you. With your support, during this special anniversary year, we can continue to boost the search for treatments.

Retina UK was formed five decades ago, and since then we have invested £17.5 million in research projects, built real momentum and achieved so much together. But we still need your help to leap forward with more cutting-edge research and continue to give hope and a home to the whole inherited sight loss community.

“Researchers like myself quite simply wouldn’t be able to carry out many of our exciting projects without the funding we receive from Retina UK and we are hugely grateful to the charity’s supporters who make our research possible.”

Professor Mariya Moosajee, a previous grantee

To make a donation to our 50th Anniversary appeal, visit [RetinaUK.org.uk/appeal](https://retinauk.org.uk/get-involved/fundraising/appeal/). If you would prefer to donate over the telephone, please call 01280 815900. You can also call us to find out how you can donate via bank transfer, text or direct debit too. To make a donation via cheque, please send it to us at Freepost Retina UK.

**Thank you** for supporting our vital work for the past 50 years and into the future.

**Text ANNIVERSARY to 70560 to donate £10** (Texts cost £10 plus one standard network rate message)**.**

## Get involved in our anniversary year

As Retina UK mark 50 years of groundbreaking work, we would love you to get involved and join #TeamRetinaUK in helping us to continue raising vital awareness and funds.

Could you organise an event in your local community, school or workplace? From bake sales to non-uniform days, challenges to talent shows, however you choose to support us, we will be with you every step of the way with advice, assistance and resources.

We are looking for more people to join us as Retina UK members. In return for your £24 yearly donation, you will be invited to vote in future AGMs (from 2026), empowering you to have your say and shape the future of our charity. To find out more, visit [RetinaUK.org.uk/membership](https://retinauk.org.uk/get-involved/donate/retina-uk-membership/).

The Retina UK Lottery has created 22 winners so far and you could be next! Do you want to be in with the chance of winning £25,000 every week, for as little as £1 a line? Visit [RetinaUK.org.uk/lottery](https://retinauk.org.uk/get-involved/donate/lottery/)to start playing today. What would you spend your winnings on?

If challenges are your thing, could you take on a rewarding race, a thrilling skydive or a memorable hike to mark our special anniversary? Our website, [RetinaUK.org.uk/challenge](https://retinauk.org.uk/get-involved/fundraising/take-on-a-challenge/), has a wide range of challenges to choose from – or suggest your own!

To have a chat with our friendly Fundraising team about your 2025 goals, please either call 01280 815900 or email [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk). We would love to hear from you.

## Congratulations to our 2025 TCS London Marathon runners

On Sunday 27 April 2025, 28 incredible Retina UK supporters took on the 45th TCS London Marathon and inspired us all. Our fantastic #TeamRetinaUK runners, made up of people living with inherited sight loss, or a loved one of someone who is, trained hard for months during the cold winter period and conquered the race in style.

The record-breaking annual event, which saw more runners than ever taking part, was a huge success. They raised a staggering £65,000+ (and counting) for our vital work. Did you spot one of our runners on the BBC coverage?

One of this year’s runners, James Treweek, ran alongside his mum Gill, who acted as James’ guide runner. He shared his reasons for taking part:

“I have a condition called retinitis pigmentosa (RP). I think that Retina UK are a great cause. My condition is genetic so it’s nice to know that my family and future generations will be supported by them.”

We still have a few places remaining for the world’s largest half marathon, the Great North Run in Newcastle on Sunday 7 September 2025. If you know someone who would like to take part, please ask them to reach out to Retina UK.

Inspired to take on a challenge of your own during our 50th anniversary year, or maybe you are interested in running the TCS London Marathon 2026? Get in touch with our Fundraising team on 01280 815900 or email [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk)to find out more.

## PAID ADVERTISEMENT: NEW OrCam Read 3

Orcam Read 3 is a highly sophisticated lightweight smart camera. Using Al technology, it instantly reads any printed or digital text from books, newspapers, smartphone screens, computers, and more. It is intuitively operated, with just the press of a button. Either listen via the mini speaker on the device or through headphones (wired or bluetooth). Orcam Read 3 is the most efficient smart pen on the market, with Speed Reading and the only one with Full Page Capture. It is designed for all ages and does not require an internet connection. The OrCam Read 3 can also be used with its included stand for hands free operation.

Perfect for those at home, work and school. Great for those with moderate low vision, reading difficulties, including dyslexia and reading fatigue.

Reads a full page with one press!

Sale price: £1,700, includes stand and speaker.

Simply point, press and listen!

Freephone: 0800 145 6115 for a FREE home demonstration or for more information.

## Dates for your diary

Activity to mark our 50th Anniversary is now underway. Details of all of our events can be found on our website [RetinaUK.org.uk/events](https://retinauk.org.uk/events/). You can also call our office for more information 01280 821334.

### JUNE

* 50th Anniversary events start
* Look Forward summer 2025 edition
* Professional networking open day (4 June)
* The 5K Wight White Cane Walk 2025 (8 June)
* ‘Talking’ Home & Garden peer support group (24 June)
* National peer support group summer meeting (26 June)

### JULY

* Jump in July 2025
* Retina UK summer raffle (1 July)
* Women’s peer support group (3 July)
* QAC Sight Village: Central – Eastside rooms Birmingham (7-8 July)
* Men’s peer support group (9 July)
* Retina UK AGM (30 July) - Online

### SEPTEMBER

* Look Forward autumn 2025 edition
* Great North Run (7 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
* National peer support group Autumn meeting (25 September)

### OCTOBER

* Retina UK Day 2025 (9 October)

### NOVEMBER

* Look Forward winter 2025 edition
* Sahara Desert Trek 2025 (6 – 11 November)
* Women’s peer support group (13 November)
* QAC Sight Village: London (18-19 November)
* ‘Talking’ Tech peer support group (25 November)
* Men’s peer support group (26 November)

### DECEMBER

* Big Give Christmas Challenge 2025 (2 – 9 December)

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

* Peer support groups: [RetinaUK.org.uk/groups](https://retinauk.org.uk/information-and-support/services/local-peer-support-groups/coming-soon)
* Webinars: [RetinaUK.org.uk/webinars](https://retinauk.org.uk/events/?filter_event_type=118&filter_location=&filter_date=&filter_submit_btn=Apply+filters)
* Challenge events: [RetinaUK.org.uk/challenge](https://retinauk.org.uk/get-involved/fundraising/take-on-a-challenge/)

### New parents and carers peer support group

Retina UK has launched a new online support group for parents and carers. We all know that being a parent or carer brings its challenges as well as its joys; add in a diagnosis of a progressive, inherited sight loss condition and those challenges can seem overwhelming! Our group provides a fully inclusive, welcoming space to bring families together, to share experiences, hints, tips, coping strategies, and ideas to help you support your young person.

Knowing that you’re not alone on this journey, having the opportunity to meet and chat with other parents who genuinely understand, or simply to listen, can make so much difference.

We want to empower you and help you recognise and manage emotions that yourself and your child or young person may be experiencing.

So whether you are also living with the condition or not, our group will provide support and information, giving a unique insight and guidance that you may find useful, as well as fostering a community in which members can share information with one another, from their own unique lived experience.

Find out more at [RetinaUK.org.uk/parents-carers](https://retinauk.org.uk/information-and-support/services/local-peer-support-groups/parents-carers/).

## Thank you

* We’d like to say a huge thank you to Evolve Estates (based in London) and Bupa Dental Care (based in Epsom) for choosing Retina UK as their Charity Of The Year partners in 2025.
* In April, Graeme Ives took on six marathons in seven days – in the Sahara Desert! Graeme decided to take on this epic challenge because his son lives with retinitis pigmentosa. He raised over £1,500 for our vital work and we’d like to say a massive thank you.
* Hayden Kent ran the Retford Half Marathon in March and raised a fantastic £505 for Retina UK for which we are so grateful! Hayden chose to support Retina UK as his son is visually impaired.
* Back in April, Karen Anglim from Cheshire organised a yummy bake sale for Retina UK and raised an amazing £300. We are so grateful to you and your supporters, Karen!
* Hilary Jones, one of our longest-serving office volunteers, supports us all-year-round with Look Forward recordings, processing our Sight Loss Survey, looking after our stamp appeal and other roles, and we want to show our appreciation by saying a huge thank you.
* In March #TeamRetinaUK was out in force at the Sheffield Half Marathon and raised over £2,000 despite the rain! Thank you to everyone who donned our vests and raised awareness and funds.
* Lucy McFarlane and the students of Blackwood School in the West Midlands raised over £4,500 for Retina UK in February with their Fitness Fortnight activities during Retinitis Pigmentosa Awareness Month. It was a huge success and we are so thankful to them all for getting involved!
* In April, Jay Seymour organised a fantastic cinema screening of the Disney+ film about living with RP, Blink, as part of his fundraising for the Sahara Desert trek in November. The event was a huge success. Thank you, Jay, for your continued support!
* As part of her training for the TCS London Marathon My Way, Natasha Evans ran the Brighton Marathon too – both in April! Natasha raised over £1,000 for Retina UK through her epic races. Thank you!

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](mailto:james.clarke@RetinaUK.org.uk). Details of all of our upcoming challenge events can be found on our website: [RetinaUK.org.uk/challenge](https://retinauk.org.uk/get-involved/fundraising/take-on-a-challenge/).

Thank you to everyone who has fundraised for Retina UK over the last few months. Please share your photos with us at [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk) or tag us on social media.

## Register now for our Professionals’ Conference

**When**: Friday 19 September 2025

**Where**: Holiday Inn, Regent’s Park, London (W1W 5EE) and online

**Register**: [RetinaUK.org.uk/prof-conf](https://retinauk.org.uk/event/professionals-conference/)

**Cost**: Free to attend

Registration is now open for our Professionals’ Conference 2025 which is open to all health, social and education professionals. Join us for a packed day of CPD accredited sessions as we mark the charity’s 50th anniversary. Along with our exhibitors, the line-up for the day is as follows:

**9:30am** Registration opens – network and visit our exhibition stands.

**10.00am** Welcome and housekeeping.

**10.05am** From vision to reality: 50 years of progress (Kathy Evans, Chair of Trustees, Retina UK).

**10.20am** Every experience counts: Insights from our Sight Loss Survey (Tina Garvey, Chief Executive, Retina UK).

**10.50am** Learning from lived experience: In conversation with our community (Paula McGrath, Deputy Chief Executive, Retina UK, leads a panel session).

**11.40am** Break

**12.00pm** Current developments in Inherited Retinal Dystrophy (IRD) research (Robert Henderson, Consultant Ophthalmic Surgeon, Great Ormond Street Hospital and Moorfields Eye Hospital).

**12.35pm** 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).

**1.10pm** Lunch

We are mixing it up a little after lunch this year with sessions delivered specifically for:

* ECLOs: An overview of the causes, symptoms and stages of Inherited progressive sight loss – Stevie Johnson, Clinical Lead, RNIB.
* Rehabilitation specialists and Habilitation specialists: Exploring some of the challenges of delivering vision rehabilitation with ethnically diverse clients – Simon Labbett, Vision Rehabilitation Specialist and Bhavini Makwana, Chair of BAME Vision.
* Optometrists: Low vision strategies: Advice and services for people with Inherited Retinal Dystrophies (IRDs) - Louise Gow, Head of Eye Health, Optometry and Low Vision at the RNIB. Association of Optometrists (AOP) accredited.

These role specific sessions are only available to in-person delegates.

* ‘Technology: creating life-changing opportunities for people with inherited sight loss’, delivered by Davinder Kullar, Personaleyes (in-person and online).

If you have any questions about our Professionals’ Conference, email [**services@RetinaUK.org.uk**](mailto:services@RetinaUK.org.uk).

**QUOTE** from Nicola, a 2024 Professionals’ Conference attendee:

“I want to thank all the Retina UK staff for such a fantastic event. A really enjoyable day. I’ve made some new connections for my role and learned a few things relating to research, people with learning disabilities and reconfirmed my knowledge of the Eye Care Support Pathway.”

## Spotlight on the Belfast ‘Bumpers’

Annemarie and Kim share the role of Local Group Facilitator for ‘Bumpers’ in Belfast, Northern Ireland. The group meets monthly and is open to anyone living with sight loss in the Belfast area. They currently have almost 40 members, supported by an incredible team of sighted volunteers.

Annemarie is a long cane user. She started to lose her sight 10 years ago and lost her job and her driving licence as a result. Kim was diagnosed with RP at the age of 18. She still retains good central vision and plays visually impaired tennis.

Describing the group, Annemarie said “I feel that we’re there for people who want to get out. They decide where they want to go and we try to facilitate that for them. We’ve had some very successful outings, including The Botanic Gardens, Christmas dinner, coffee mornings, walks and this month we are going to Rathlin Island to see the puffins. It’s just lovely to go to places that people wouldn’t normally travel to, or wouldn’t go on their own!”

They have fond memories of their past meetings including a talk at Ulster University, a coast walk and going for lunch and ice cream.

Annemarie describes volunteering as something she gets great pleasure and a sense of achievement from. “You always find out something different about somebody. It’s a lovely thing to do. People have supported me and it’s my turn to give something back!”

Kim previously lived in South Africa. When she arrived in the UK she was excited to see the dynamic work going on at Retina UK and wanted to be a part of it.

She said: “I have met the most extraordinary people with such inner strength and resilience. How amazing other people are - that gives me strength to see life differently. We can’t afford to look inwards and to feel sorry for ourselves on any level. If we don’t live this life we’re going to lose it. I get inspiration from the people I meet. I get inspiration from Annemarie and every other ‘Bumper’ in our group.”

Kim is also part of the ‘Talking’ Tech and ‘Talking’ Travel online groups which are available to everyone. These special interest groups meet bi-monthly on Zoom.

Asked if they would recommend volunteering to others, they both wholeheartedly agree.

“I wish that people would actually volunteer more because it’s so enriching. I think that if people volunteer and give up their time, what you give out, you get back so hugely.”

“It changes people’s lives. Sometimes we are aware of people who are feeling quite down, insular or can’t get past the front gate. It’s so important what we do.”

If you are interested in starting a peer support group in your area or if you would like to volunteer for Retina UK, please get in touch by emailing [volunteering@RetinaUK.org.uk](mailto:volunteering@RetinaUK.org.uk) or call us on 01280 821334.

## Support our work

* £10 could pay for the primers required for the DNA analysis that detects disease causing mutations that result in RP.
* £50 could pay for one hour of super resolution microscope imaging, allowing scientists to visualise how light sensing photoreceptors are damaged in RP.
* £100 could pay for one PhD student for a day.

### Phone donations

If you would like to make a donation via telephone, please call our Fundraising team on 01280 815900.

Your generosity will make a tangible difference to our community as we enter our 50th anniversary year.

Thank you in advance.

### Text donations

A simple and quick way to give!

* Text LFFIVE to 70560 to donate £5
* Text LFTEN to 70560 to donate £10
* Text LFTWENTY to 70560 to donate £20

Text donations will be added to your monthly phone bill and will cost your donation plus one standard network rate message.

### Cheques

If you would like to donate by cheque, please forward it to us at Freepost Retina UK.

Look Forward is available as a hard copy, by email, audio (CD or memory stick) 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](mailto:info@RetinaUK.org.uk).