

# Retina UK Professionals' CONFERENCE 2025



Working together to make the biggest difference for families affected by inherited sight loss.



**19 SEPTEMBER  
2025**



**The Holiday Inn, Regent's Park, London**



**[RetinaUK.org.uk/prof-conf](https://RetinaUK.org.uk/prof-conf)**



## **Tribute to Lynda Cantor MBE**

Our founder and honorary president Lynda Cantor MBE sadly passed away on Thursday 21 August 2025. We are all deeply saddened by this news.



Lynda founded the charity 50 years ago and continued to serve as a Trustee until recently. She was the driving force behind the charity's development from a small community group to the respected national organisation it is today.

Lynda made a huge impact for thousands of people living with inherited sight loss throughout the charity's history.

Her unwavering commitment, determination and vision were fuelled by the impact of retinitis pigmentosa on her own life.

When Lynda formed The British Retinitis Pigmentosa Society (BRPS) in 1975, little could she imagine the organisation that Retina UK has become.

Since the first fundraising garden party in 1975 (which made a profit of £187) Retina UK has invested more than £18 million into ground-breaking research and huge advances have been made into unlocking the causes of inherited sight loss and developing potential treatments.

Lynda was recognised for her work with the award of an MBE in 1994. She was also involved in the formation of Retina International.

Lynda was the lifeblood of our charity for 50 years and a true force of nature. She was a beacon of hope for the community and will always remain a source of inspiration for all those who were fortunate enough to meet her.

She will be sadly missed by the trustees, staff, volunteers and all those involved with Retina UK over the years. Our thoughts are with her family at this sad time.

# Welcome

Welcome to the Retina UK Professionals' Conference 2025.

We aim to support you, our professional colleagues, to make the biggest difference for families affected by inherited sight loss. Following the introduction of our Professionals' Pack in 2024 we have seen the number of referrals to Retina UK increase substantially. We want you to feel confident about the ways our services can complement your work. We are pleased to offer CPD accreditation for today's conference.

Whether you are attending online or in-person, thank you for joining us. Our programme includes a community panel who have generously agreed to share what it means to live with an inherited sight loss condition.

If you're joining us in person, please visit our exhibitors, chat with the Retina UK team and to other delegates. If you are joining us online, we encourage you to ask questions and share your thoughts using the Q&A button.

We are very grateful to all of our sponsors and exhibitors for their support.

Enjoy the day,

A handwritten signature in black ink, appearing to read 'Tina Garvey', with a stylized flourish at the end.

Tina Garvey  
Chief Executive, Retina UK



**We need you:** Donate to our **50<sup>th</sup> Anniversary Appeal** and support our vital search for future treatments.

You can either text **ANNIVERSARY** to **70560** to donate **£10**, or you can kindly donate via our website or by calling us:

**[RetinaUK.org.uk/appeal](https://RetinaUK.org.uk/appeal)**

**01280 815900**

**[fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk)**



# Sponsors

Thank you to our event sponsors for their support in delivering the Retina UK Professionals' Conference 2025.

## Johnson & Johnson

This conference is part funded through sponsorship from Johnson & Johnson. They have had no control or influence over the agenda or content.

Other sponsors in 2025 include AAVantgarde, Alkeus Pharmaceuticals, Beacon Therapeutics and Octant Inc.



# Delegate information

A digital version of this programme, including an audio recording, is available on our website: [RetinaUK.org.uk/prof-conf](https://RetinaUK.org.uk/prof-conf) or by scanning the QR code(s) on page 9.

## Wifi

Free wifi is available for in person delegates. Join at IHG connect Wifi, using password SMILE.

## Questions

If you are attending remotely, you will not be able to raise your hand to ask questions on the day. If you do have a question, please submit it via the Q&A button in Zoom.

## CPD accreditation

The Retina UK Professionals' Conference is accredited with CPD Standards. A total of 5.5 CPD points will be awarded to delegates for attending the full Conference (in-person and online). Attendance by online delegates will be monitored and certificates will be awarded based on evidence of full attendance.

The in-person role-specific session for eye care professionals will be accredited separately by the Association of Optometrists (AOP) with two (2) interactive points which will be issued by Retina UK. These delegates will receive 3.5 points from CPD Standards for the morning session from Retina UK.

Online delegates should ensure that their screen name matches the name used to register for the event.

**CPD Certificates will be issued** following receipt of a completed feedback form (see below) by Retina UK. Certificates will start to be issued one week after the Conference ends.

## **Online attendees - Zoom link**

If you are joining us online, please use this link:

**<https://us02web.zoom.us/j/85745369760>**. We will also make this link available on the home page of the Retina UK website for ease of navigation.

## **Social media**

We'll be posting throughout the day on social media. If you are sharing thoughts about the Conference, please use the hashtag **#RetinaUKConf**.

## **Recordings**

Recordings of Conference presentations, excluding the in-person role-specific sessions, will be sent to both online and in-person delegates.

## **Feedback**

Your views are important to us, please take a few minutes to share your feedback after the event by completing the form here: **[RetinaUK.org.uk/feedback-profs25](https://RetinaUK.org.uk/feedback-profs25)**.



A circular inset image showing a pile of colorful bingo balls. The balls are in various colors including red, yellow, orange, blue, green, and purple. Each ball has a white circular label with a black number. The numbers visible include 10, 33, 07, 25, 28, 49, 47, 40, 33, 56, 44, and 5. The balls are piled together, creating a sense of depth and randomness.

**Join our Lottery and you  
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week - for just £1 a line!  
Sign up today:**



**RETINAUK.ORG.UK/LOTTERY**





## Zapvision / Navilens QR codes

We are pleased to be providing information and signage at our 2025 Conferences using Zapvision and NaviLens.

Zapvision helps people who are blind or low vision access product information on packaging, with a single, Accessible QR code. These accessible QR codes will work within Seeing AI, Envision and BeMyEyes, which may already be installed on your device. Alternatively, you can download the Zapvision app, available on iOS and Android.

For those who attended our Conferences in 2024, we are also using NaviLens ([navilens.com/en](https://navilens.com/en)).

Please feel free to use whichever option works best for you.



Navilens QR code



Zapvision QR code

We hope you enjoy the conference. It is important to us that our events are accessible to everyone, and for this reason we make no charge. As a charity, we rely on support from people like you to continue delivering events like this, as well as the rest of our vital work. Please consider making a donation at [RetinaUK.org.uk/donate](https://RetinaUK.org.uk/donate) or visit the Retina UK stand in the exhibition area.

# Programme

**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**

**2.00pm**

**Technology: creating life-changing opportunities for people with inherited sight loss**

Davinder Kullar, Personaley

**2.00pm**

**ECLOs - An overview of the causes, symptoms and stages of Inherited progressive sight loss**

Stevie Johnson, Clinical Lead, RNIB

**2.00pm**

**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

**2.00pm**

**Eye care professionals - 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

**3.30pm**

**Final reflections and feedback** (in workshop rooms)

**4.00pm**

**Close**





**Kathy Evans,  
Chair of Trustee Board, Retina UK**

After graduating in law from the University of Liverpool, Kathy Evans secured a training contract with KPMG and qualified as a chartered accountant. She held finance roles with the Arts Council of Great Britain and the TSB Group before moving into the charitable sector. She managed the finances for a number of charities before joining the Royal College of Ophthalmologists (RCOphth) as its Accountant.

She was appointed Chief Executive of the College in 2004 and served until her retirement in 2023. Working with colleagues, College Officers and members, she was responsible for the College's day-to-day management. During her tenure the organisation grew, became more professional, more outward looking and more complex.

She is a member of the Links Network Advisory Committee, run by the International Centre for Eye Health.

In retirement she passed the Diploma in Medical History organised by the Worshipful Society of Apothecaries.

Kathy joined Retina UK as Chair of Trustees in September 2024. She has long admired the work of the charity and has enjoyed meeting many of the people connected with it.



**Tina Garvey**  
**Chief Executive, Retina UK**

Tina Garvey is Chief Executive at Retina UK. Since joining the charity, in August 2015, the organisation has significantly grown its information and support services, and work toward funding medical research to find effective treatments for inherited progressive sight loss conditions.

Tina plays an active role within the vision sector, such as becoming a Liveryman of the Worshipful Company of Spectacle Makers. She leads a team committed to making sure that our community is being heard and getting the very best information and services, and that the charity has the greatest possible impact.

Tina has more than 20 years' experience in the charity and public sector. She has a BSc in Science and Social Sciences, a postgraduate diploma in Marketing, an MSc in Leadership and Management in Public Services and a Masters in Law. She was awarded a Honorary Fellowship from the University of Hertfordshire in 2024.



**Paula McGrath**  
**Deputy Chief Executive, Retina UK**

Paula McGrath is Deputy Chief Executive at Retina UK.

She joined the health charity sector in 2006, following an early career as a journalist. She led the communications teams at the PSP Association, Education for Health and Motor Neurone Disease Association before joining Retina UK in 2018.

Paula is passionate about making an impact for families affected by rare conditions. She uses audience insight to ensure organisational development is designed to meet the needs and aspirations of the communities being served. In 2019, Paula introduced the first Retina UK Sight Loss Survey and in response to the findings has overseen the creation of new resources including Unlock Genetics and Discover Wellbeing and the development of our offering for professionals.

Paula represents Retina UK at numerous external meetings and groups including the All Party Parliamentary Group on Eye Health and the Vision Partnership.

Paula holds the Coaching Skills Certificate with the Association of Executive Coaches.





**Robert Henderson, Consultant  
Ophthalmic Surgeon, Great  
Ormond Street Hospital and  
Moorfields Eye Hospital**

Robert Henderson is a Consultant Paediatric Ophthalmologist and Adult & Paediatric Vitreoretinal Surgeon at Great Ormond Street Hospital and Moorfields Eye Hospital, and an Honorary Associate Professor at the UCL-GOSH Institute of Child Health. He specialises in the surgical and genetic management of paediatric retinal diseases.

Robert leads the inherited retinal dystrophy clinic at Great Ormond Street Hospital and has established an innovative dual sensory clinic serving families affected by combined visual and hearing impairments. He directs the Voretigene ocular gene therapy programme at Great Ormond Street Hospital and serves as the North Thames Specialty Lead for Ophthalmic Genomics.

Mr Henderson serves as principal surgeon for ongoing gene therapy trials addressing USH1B (AAVantgarde) and RPGR-related X-linked retinitis pigmentosa (BEACON Therapeutics). He is also actively involved in pioneering approaches for subretinal photoreceptor stem cell delivery.

His clinical and research interests are dedicated to developing and delivering innovative therapies for rare inherited retinal diseases.



**Michael Crossland, Senior  
Research Fellow, University  
College London (UCL) Institute of  
Ophthalmology**

Michael Crossland is a principal optometrist at Moorfields Eye Hospital and a senior research fellow at University College London. He has worked in the NHS low vision clinic at Moorfields for over 25 years, in which time he has met thousands of children, adolescents and adults. He researches mental health and wellbeing in people with vision impairment, with a particular focus on young people with inherited retinal disease. He is also interested in the use of new technology by people with low vision.



**Rachel Canavan, PhD student,  
University College London (UCL)  
Institute of Ophthalmology**

Rachel Canavan is a PhD student at the UCL Institute of Ophthalmology, funded by Moorfields Eye Charity. She has a background in psychology and child mental health. Her research is focused on the mental health and wellbeing of children and young people with vision impairment. The goal of her PhD research is to identify risk and resilience factors to inform the recommendation of the development of a package of supportive interventions for young people, designed in collaboration with individuals who have lived experience.



## Stevie Johnson, Clinical Lead for RNIB's Eye Care Support Team

Stevie Johnson is the Clinical Lead for RNIB's Eye Care Support Team and leads on Eye Care Liaison Officer (ECLO) training and ensuring services are consistent and professional through the development and maintenance of Quality Standards and resources.

## DOUBLE YOUR DONATION: 2 - 9 DECEMBER!

During our 50<sup>th</sup> anniversary year, Retina UK will be taking part in the Big Give Christmas Challenge. For one week this December, your donation will be matched and therefore doubled.

If you have any queries or you would like a reminder once the campaign starts, please contact us on either **01280 815900** or email **[fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk)**.

**"I thought that my life was done at 31 and there was no help for me. While working as a Prison Officer, I fell into a very dark place. RP was the main factor of the stress, fear and doubt clouding my mind and dragging me further and further down a horrible path."**





## **Simon Labbett, Chair, Rehabilitation Workers Professional Network**

Simon Labbett has been active in the sight loss sector since 1988, beginning his career with the Royal National Institute of Blind People as a Braille music transcriber, before becoming interested in music and art for vision impaired people.

Initially qualifying as a Vision Rehabilitation Specialist in 2005, he completed a BSc in Complex Needs Rehabilitation Work (visual impairment) at Birmingham City University in 2018.

In 2013 Simon played a pivotal role in establishing and chairing the first professional body in the UK for Vision Rehabilitation Specialists. The Rehabilitation Workers Professional Network (RWPN) is now 12 years old and has over 500 practitioners and students as members. In 2022 he guided RWPN's work in gaining accredited register status for its professional register with the Professional Standards Authority.

Simon works full time as a Vision Rehabilitation Specialist in the Sensory Needs team within the City of Bradford's social services. In 2023 he was visiting lecturer at Glasgow Caledonian University delivering modules on the Low Vision Rehabilitation postgraduate diploma.

In 2025 he was awarded an Honorary Doctorate by Birmingham City University for his work in the sector and in developing a professional body for Vision Rehabilitation Specialists.



## **Bhavini Makwana, Policy and Campaigns Manager for Thomas Pocklington Trust and Chair of BAME Vision**

Bhavini Makwana works as a Policy and Campaigns Manager for Thomas Pocklington Trust and is the Chair of BAME Vision, which she founded in 2020. She is also the London and South East Group Facilitator and an Ambassador, for Retina UK.

Bhavini was diagnosed with retinitis pigmentosa when she was 17 and received vital rehabilitation support 12 years after her diagnosis, which she describes as 'life changing'. She now ensures that everyone is aware of rehabilitation support and how to access it. She is a mother, wife, and a proud owner to her beautiful and full of character Guide Dog Colin.

Bhavini aims to empower those with vision impairment by sharing resources (including lived experience stories) and signposting to information. She aims to break down barriers and stigma around sight loss and eye health in ethnic minority communities. She champions and advocates for an accessible, inclusive, and equitable society for blind and partially sighted people to live and thrive in.

Visit [bamevision.org](https://bamevision.org) for a variety of blogs, vlogs, webinars and much more.



## **Louise Gow, Head of Eye Health, Optometry and Low Vision at the RNIB**

Louise Gow, Head of Eye Health, Optometry and Low Vision at the RNIB. Association of Optometrists (AOP) accredited.



## **Davinder Kullar, Personaley**

Davinder Kullar is a first generation Indian born in the UK. He was diagnosed with retinitis pigmentosa as a young teenager and said that “learning to adapt to each change experienced was the key to success”.

Part of his toolkit has been technology. Combining this with his ability to communicate complex things in simple ways, has allowed him to have a career in teaching, coaching and mentoring others with low or no vision.

He has worked in the sector for over 10 years and has recently set up his own business and consultancy, continuing to teach, coach and mentor people. He believes people can reach their potential with the right mix of attitude, skills acquisition and removing barriers.



## How we can support you in your role: Services from Retina UK

Whether you are a professional looking for information for yourself, or practical or emotional support for your clients, online, by phone or face-to-face, we're here to help. All of our services are free to access and offered in a range of accessible formats. These include:

### **Website – [RetinaUK.org.uk](https://RetinaUK.org.uk)**

A wealth of information on inherited sight loss, available support and current research. This includes a section specifically for professionals.

### **Helpline: 0300 111 4000 | [helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk)**

Our Helpline team are here to support you and your clients. They can answer your questions and signpost to other sources of information. Those affected by inherited sight loss can speak with our volunteers with lived experience.

### **Discover Wellbeing – [RetinaUK.org.uk/wellbeing](https://RetinaUK.org.uk/wellbeing)**

Our online course helps people affected by inherited sight loss to develop an awareness of emotional wellbeing and the practical skills to adapt to life's ups and downs. It includes a CPD-accredited course called Supporting Others, designed specifically for professionals.

### **Unlock Genetics – [RetinaUK.org.uk/genetics](https://RetinaUK.org.uk/genetics)**

Our Unlock Genetics resource provides clear, trustworthy and balanced information on genetics, inheritance patterns, accessing a genetic test and genetic counselling. It also provides information on how to make appropriate referrals for genetic counselling and testing.

## **Events – [RetinaUK.org.uk/info-events](https://RetinaUK.org.uk/info-events)**

We hold events online and face-to-face, including our Annual Conference and Professionals' Conference. We also organise webinars for professionals and those living with inherited sight loss.

## **Newsletters – [RetinaUK.org.uk/resources](https://RetinaUK.org.uk/resources)**

Sign up to receive the latest news from Retina UK, including our emails specifically for professionals. Choose which format is best for you.

## **Talks and presentations**

Our staff and community members with lived experience are happy to share their knowledge and expertise. We regularly deliver presentations for groups of professionals online and in person. Interested? Email [services@RetinaUK.org.uk](mailto:services@RetinaUK.org.uk).

## **Peer Support Groups – [RetinaUK.org.uk/groups](https://RetinaUK.org.uk/groups)**

Groups meet in person or virtually and are a welcoming, safe and friendly place for people to share experiences, tips and information and form friendships.

## **Other resources**

- YouTube ([@RetinaUK](https://www.youtube.com/@RetinaUK))
- Podcast on [Spotify](https://open.spotify.com/), Apple and Google podcasts,
- Facebook groups:
  - [facebook.com/groups/retinauklocal](https://facebook.com/groups/retinauklocal)
  - [facebook.com/groups/therpgroup](https://facebook.com/groups/therpgroup)

Sign up to receive our information [RetinaUK.org.uk/mailing-list](https://RetinaUK.org.uk/mailing-list), email [info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk) or call 01280 821334.



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](http://www.sightandsound.co.uk)



**Call**  
**0800 085 6055**

Contact us for more information



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