



Retina UK Professionals' Conference 2026

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



18 September 2026



Edgbaston Park Hotel and Conference Centre, Birmingham



THE CPD STANDARDS OFFICE
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2024-2026
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Welcome

Welcome to the Retina UK Professionals' Conference 2026. We are pleased to offer CPD accreditation for today's event.

Working together, we can make the biggest difference for everyone affected by inherited sight loss. We really are #StrongerTogether.

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

Please share your feedback with us (**RetinaUK.org.uk/feedback-profs26**) so that we can tailor future events to better suit your needs. A link to the recordings from the day (except for the role-specific sessions) will be emailed to you around one week after the Conference.

Our Conference is free to attend thanks, in part, to the generous support of our sponsors and exhibitors, but it is a significant financial investment. A donation towards the cost of your attendance would be gratefully received.

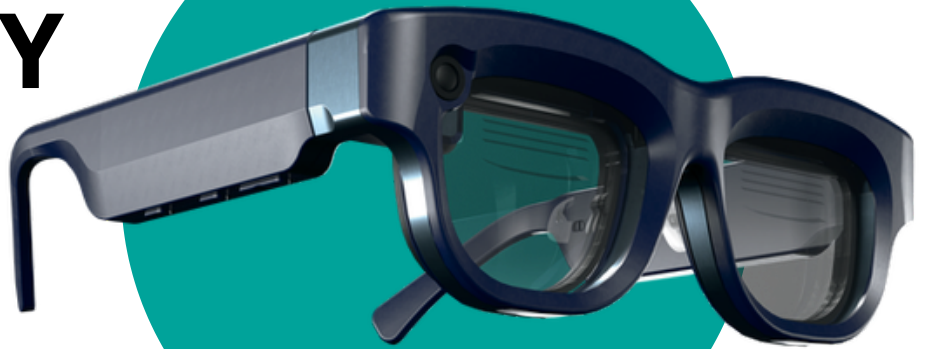
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Tina Garvey
Chief Executive, Retina UK

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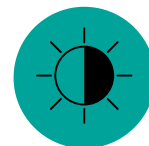
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They have had no control or influence over the agenda or content.



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Delegate information

A digital version of this programme, including an audio recording, is available on our website: RetinaUK.org.uk/prof-conf.

Wi-Fi

Free Wi-Fi is available for in-person delegates. Select **Edgbaston Park Hotel Guest Wi-Fi Ask4** and then add your first name and surname.

Registration desk (in-person attendees)

We are trialling the use of an online check-in facility in 2026 for our in-person delegates. You will have received a QR code in your registration confirmation. Simply show this to our team on arrival. If you would prefer to check-in at our registration desk instead, please feel free to do so.

Online attendees - Zoom link

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

<https://us02web.zoom.us/j/82846151989>. We will also make this link available on the home page of the Retina UK website for ease of navigation.

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. We will be taking questions at the end of each session.

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.

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-profs26.

Your responses will help to shape next year's Conference so that our events continue to be relevant and reflect what our community wants.

We receive generous sponsorship to help cover the cost of the event and we need to provide feedback to our sponsors to show that people found it helpful. We need your feedback to share with our sponsors which will help secure funding for future events.



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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.

Zapvision / Navilens QR codes

We are pleased to be providing information and signage at our 2026 Conferences using Zapvision and NaviLens. 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** or visit the Retina UK stand in the exhibition area.

Programme

9.00am

Registration opens

Network and visit our exhibition stands

10.00am

Welcome and housekeeping

10.05am

Welcome from our Chief Executive

Tina Garvey, Chief Executive, Retina UK.

10.10am

From innovation to independence: assistive technology for inherited sight loss

Our panel of experts share their professional and personal experience to bridge the gap between cutting-edge innovation, including AI, and everyday reality.

10.55am

Strengthening genetics conversations in IRD care: community and clinical perspectives

Dr Henry Stennett, Senior Research Coordinator, Retina UK. Sian Sperring, Ophthalmology Genetic Counsellor, Oxford Eye Hospital. Rob Sears, who is living with inherited sight loss.

11.35am

Break

11.55am

Approaching difficult conversations, a framework

Professor Susan Downes, Consultant Ophthalmologist Oxford Eye Hospital and Honorary Clinical Senior Lecturer at Oxford University. Dr Amanda Salisbury, Consultant Clinical Oncologist at Oxford University Hospitals NHS Trust. Clare Abbott, Senior Eye Clinical Liaison Officer.

12.35pm

Learning from lived experience: in conversation with our community

A panel session with members of our community. Paula McGrath, Deputy Chief Executive, Retina UK.

1.35pm

Lunch



2.20pm

Nothing about us without us – supporting research participation (in-person and online)

Kate Arkell, Research Director, Retina UK; Mark Baxter, Information and Support Coordinator, Retina UK; James Moore, who is living with sight loss.

2.20pm

Rehabilitation specialists and Habilitation specialists: Family dynamics and the timing of services for people with IRDs (in-person only)

Richard Bounds, CEO of Rehabilitation Workers Professional Network

2.20pm

ECLOs: An overview of Usher Syndrome and Stargardt's Disease and how ECLOs can best support those affected (in-person only)

Angela O'Kane, RNIB ECLO Service Manager (Northern Ireland).

2.20pm

Low vision and Optometrists: Experiential learning activities workshop (in-person only)

Louise Gow, Head of Eye Health, Optometry and Low Vision, RNIB; Winnie Smith, Training and Development Manager, Health and Social Care Training Team, RNIB.

2.20pm

QTVIs: Working with CYP with inherited retinal conditions to support their emotional needs and advocacy skills. A QTVI perspective. (in-person only)

Caireen Sutherland, Programme Lead and Senior Lecturer for the Mandatory Qualification (MQ) in MSI / deafblindness at Seashell Trust

3.20pm

Reflections / action points / feedback forms.

3.30pm

Close

Conference Speakers

Clare Abbott

Senior Eye Clinic Liaison Officer (ECLO)



Clare Abbott is the Senior Eye Clinic Liaison Officer (ECLO) at the Oxford Eye Hospital, where she has worked as an ECLO for over seven years.

Clare is a registered Nurse who started her career in healthcare over 20 years ago. With a background in Emergency Nursing, Surgical and Specialist Community Practice, Clare came to the ECLO role after a career break in which she had her children and ran a business as an artist. Originally believing her time as an ECLO would be a stepping stone back into Nursing, she fell in love with the role and has stayed.

Over the years, with support from the Ophthalmology and Optometry services, she has reshaped the ECLO service in Oxford, successfully expanding the team and the reach of the ECLO service. She was appointed to the newly created post of Senior ECLO in November 2025.

Clare is involved on a daily basis in conversations regarding visual impairment and its impact.

Kate Arkell

Research Director, Retina UK



Kate Arkell studied Physiological Sciences at Newcastle University before starting her medical research charity career at the Motor Neurone Disease Association. She has learned a huge amount about science communication, grant administration and the range of ways in which charities can facilitate research progress. Kate moved on to a research management role at the Progressive Supranuclear Palsy Association before joining Retina UK.

She is excited by the very clear progress towards effective treatments for inherited sight loss and is keen to facilitate engagement with research by the Retina UK community.

Mark Baxter **Information and Support** **Coordinator, Retina UK**



Mark Baxter is the Information and Support Coordinator for Retina UK, where he combines his professional expertise with his lived experience of Retinitis Pigmentosa (RP). He manages key support services, connects individuals with essential resources, and champions accessibility.

Living with RP himself, Mark is deeply passionate about assistive technology - both in implementing daily solutions and exploring new innovations - and dedicates his career to ensuring no one navigates inherited sight loss alone.

Richard Bounds



Richard Bounds is CEO at the Rehabilitation Workers Professional Network (RWPN), the professional body overseeing standards and the Accredited Register for Vision Rehabilitation.

He has enjoyed a long career in sight loss and sensory services, qualifying as a Vision Rehabilitation Specialist himself in the mid-90s. Richard has held practitioner, volunteer and leadership roles in charity and public sector settings and is trustee and chair of a charity supporting Deaf people.

He has a passion for empowering people to achieve their chosen goals, and for collaborating with partners to create person-centred solutions that really work.

Richard has led various sector projects, including creating the apprenticeship standard for the rehabilitation qualification and the development of multiple services for both children and adults with sensory needs.

Keith Dear



Keith Dear serves as the AI Trailblazer and Technology Advisor for Sensory Services by Sight for Surrey. He specialises in bridging the gap between cutting-edge innovation and daily practicality for individuals who are blind or partially sighted. In his role, he provides information, guidance, and training on specialist Information and Communication Technology (ICT).

Keith's key responsibilities and focus areas are AI & Advanced Tech Integration. He also co-hosts bi-monthly 'Let's Talk Tech' interactive webinars highlighting built-in accessibility features across several different platforms.

Ellie Dowdy, Retina UK Tech Peer Support Group volunteer



Ellie was diagnosed with Stargardt disease in 2022 just before she sat her GCSE exams.

She is currently studying a Level 3 in Digital and Cyber Technologies at college. As part of this course, she took part in a work experience placement with HumanWare, a company who develop solutions which enable people living with visual impairment and vision loss to develop their potential and maintain their autonomy.

In her spare time, she takes part in Taekwondo, competing in competitions and helping to teach lower grades.

She said “although the diagnosis has changed the way I have to do things, it does not have the power to change my future plans, that lies in my hands”.

Professor Susan M Downes MBChB, MSc, MD(R), FRCOphth



Professor Susan Downes has been a Consultant at the Oxford Eye Hospital, Oxford University Hospitals University NHS Foundation Trust since 2000. She completed post-residency clinical and research fellowships in Medical Retina at Moorfields Eye Hospital, during which she obtained a higher degree (MD 2000) in inherited retinal degeneration (IRD) at the Institute of Ophthalmology, UCL, and Moorfields Eye Hospital.

She is a Professor of Ophthalmology at the University of Oxford. Susan was awarded a gold medal by the Oxford University Hospitals Foundation NHS Trust for outstanding achievement (2014) and was in the 2021 Top List of Women in European Vision Research and Ophthalmology.

Susan is the director of the Oxford Kellogg Vision Centre set up and launched in 2025 with the aims of creating an information hub for students with visual impairment working with a VI network, raising awareness of visual impairment with regular lectures and seminars and to support innovative research into visual impairment.

Her main clinical and research interests include inherited retinal dystrophies and acquired retina and macular diseases.

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 towards 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 an Honorary Fellowship from the University of Hertfordshire in 2024.

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



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

Anna Holloway, Retina UK Tech Peer Support Group volunteer



Anna Holloway is a DeafBlind young adult currently studying for a BSc in Applied Computing.

Born profoundly deaf and later diagnosed with Usher Syndrome Type 1D, she is passionate about accessible technology and how innovative solutions can help people with sensory impairments live more independently.

Barrie Lane, IT & Assistive Technology Training, Beacon Centre for the Blind



Barrie Lane is registered blind and has retinitis pigmentosa (RP). He currently works at the Beacon Centre for the Blind as an IT and Assistive Technology Trainer, where he supports individuals in adapting to sight loss by developing their digital skills and confidence.

Barrie began his career in the sight loss sector in 2023 as an Enablement Officer with Focus Birmingham. Prior to this, he worked as a self-employed Accessibility Assessor, collaborating with organisations including the Premier League and the Racecourse Association to improve the accessibility of their venues and events.

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.

James Moore



James, 25, a civil servant, was diagnosed with X-linked RP at the age of six in a hospital in Paris where his family was living at the time.

An opportunity promoted through the Retina UK lived experience panel resulted in a dream coming true for James. He is taking part in a clinical trial for XLRP that uses gene therapy to restore and maintain vision.

James feels extremely fortunate to have been given this opportunity. "Taking part in a clinical trial is extremely full on, and there's an abundance of testing and experimentation involved, but none of it ever bothered me because I was just grateful to be there the whole time," he said.

"It's a genuine honour to be one of the first people in the world to undergo that procedure."

Angela O’Kane, RNIB ECLO Service Manager NI



Angela O’Kane gained BSc Optometry, completing pre-reg in Glasgow Eye Infirmary and gaining MCOptom in 1999.

She worked as Optometrist across GB and Ireland for several years, going on to work in and lead family and emotional support third sector organisations. She was awarded an MBA from Queen’s University Belfast in 2014.

Angela has been RNIB ECLO Service Manager NI since 2017 and has an interest in developing training for the eye health and care sector.

Dr Amanda J Salisbury, MA DM MRCP FRCR



Amanda Salisbury is a Clinical Oncologist, a Consultant at the Oxford University Hospitals NHS Foundation Trust with a practice in Skin Cancer, and a strong interest in the communication skills needed to provide effective, compassionate care.

Dr Salisbury qualified in Medicine from the University of Oxford and undertook general medical training in London. She returned to Oxford to complete her specialist training in Oncology and a laboratory-based research degree.

Amanda has always been a keen teacher and a trainer since her own training days and has developed this interest throughout her career. She is a Nuffield Lecturer in Clinical Medicine to Lincoln College, Oxford. She has also been an examiner, and is an educational supervisor, for the Royal College of Radiologists with responsibilities for the specialist doctors in training. She lectures annually on the medical student finalists' revision course, and on the Oxford MSc course in Experimental Therapeutics.

In recent years she has become interested in exploring communication skills in other specialties, especially in how to break bad news, and she has delivered talks to Ophthalmologists, trainees and Allied Health professionals involved in eye care. The challenges of these difficult conversations in Ophthalmology mirror some of those in Oncology and it is helpful to explore a common approach.

Rob Sears, Community Member



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/channel/UCBlindFocusRS)), 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 but has discovered recently, after genetic testing, that his diagnosis is in fact Choroideremia.

Dr Henry Stennett, Senior Research Coordinator, Retina UK



Dr Henry Stennett is a biomedical researcher turned science communicator. He helps people understand complex research and the difference it can make. Henry currently works at Retina UK and has previously held roles in research communications, medical writing, and fundraising, including at Cancer Research UK. He completed a PhD in Synthetic Biology at the University of Bristol, where he worked on discovering new antibiotics. In his spare time, he enjoys writing short stories, travelling to new places, and cheering on Arsenal.

Winnie Smith, Training and Development Manager, RNIB



Winnie moved into designing and delivering training after a career in teaching, joining the Health and Social Care Training team in 2023. Winnie now manages the team, which support people working in health and social care across the UK to provide better care for people with sight loss.

Sian Sperring, Specialist Ophthalmology Genetic Counsellor, Oxford Eye Hospital



Sian Sperring has over 10 years' experience supporting patients and families affected by inherited eye conditions.

She completed an MSc in Genetic Counselling at Cardiff University and is passionate about helping individuals and their relatives understand the genetic basis and wider family implications of inherited eye disorders. She is committed to genetic education within ophthalmology and advocates for improved care and support for people living with visual impairment.



Caireen Sutherland

Caireen Sutherland, Programme Lead and Senior Lecturer for the Mandatory Qualification (MQ) in MSI/deafblindness at Seashell Trust

Caireen is a Qualified Teacher of the Visually Impaired (QTVI) and Qualified Teacher of Multi-Sensory Impairment (QTMSI) and has worked in a variety of roles in education.

Currently she works as Programme Lead and Senior Lecturer for the Mandatory Qualification (MQ) in MSI/deafblindness at Seashell Trust, training teachers to be specialist teachers in deafblindness.

Alongside this role Caireen continues to work 1-1 with children with VI and MSI in schools and homes. She is also co-chair of NatSIP and is doing this workshop on behalf of VIEW where she is a committee member.

Bhavna Tailor



Bhavna is the CEO and one of the founders of Stargardt's Connected.

Bhavna's son, Ethan, was diagnosed with Stargardt's in 2015 at the age of seven. After the initial shock, she was keen to set up a Stargardt's patient group with the aim to create a supportive community, as well as raising awareness and funds for research and support.

Bhavna has presented globally and sits on a number of national and international advisory groups for Inherited Retinal Disease research projects.

She has been awarded the Prime Minister's Points of Light Award for recognition for her work with Stargardt's Connected.

Ethan Tailor



Ethan is an 18-year-old with a passion for cooking who, after completing his A-levels, will begin a degree in Culinary Industry Management at university this autumn.

Diagnosed with Stargardt's disease at the age of seven, he is an active advocate for children and young people living with the condition.

He is a member of the Moorfields Young Persons' Advisory Group (Eye-YPAG), where he contributes to research by ensuring young people's perspectives are represented.

He has presented internationally on advocating young people's voices in research and trained as a Young Interview Assistant to gather feedback from young people participating in clinical trials. He has also presented at an international level about his lived experience of having Stargardt disease.

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How we can support you: 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

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

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.

Unlock Genetics – 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

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

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.

Peer Support Groups – 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/track/RetinaUK)
- Facebook groups:
 - facebook.com/groups/retinauklocal
 - facebook.com/groups/therpgroup

Sign up to receive our information RetinaUK.org.uk/mailing-list, email info@RetinaUK.org.uk or call 01280 821334.

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