RETINA UK
WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

Retina UK Annual Conference 2026

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

19 September 2026

Edgbaston Park Hotel and Conference Centre, Birmingham

Welcome

Welcome to the Retina UK Annual Conference. I am so pleased that you have joined us today.

Our Conference is free to attend thanks, in part, to the generous support of our sponsors and exhibitors. We have a packed programme and I encourage you to ask questions either following the sessions or later in the day.

If you are with us in Birmingham, please visit our exhibitors and chat with Retina UK staff, volunteers and our fantastic speakers. Thank you to them all for being with us today.

The morning introduces the importance of clinical trials and how to get involved if you would like to, and assistive technology. After lunch we are excited to showcase the incredible advances in stem cell-derived therapies for inherited retinal disease. We really have come so far in the past 50 years and we are closer than ever before in our search for a treatment that I know so many of our community have been waiting for.

Enjoy the day.

Tina Garvey
Chief Executive, Retina UK

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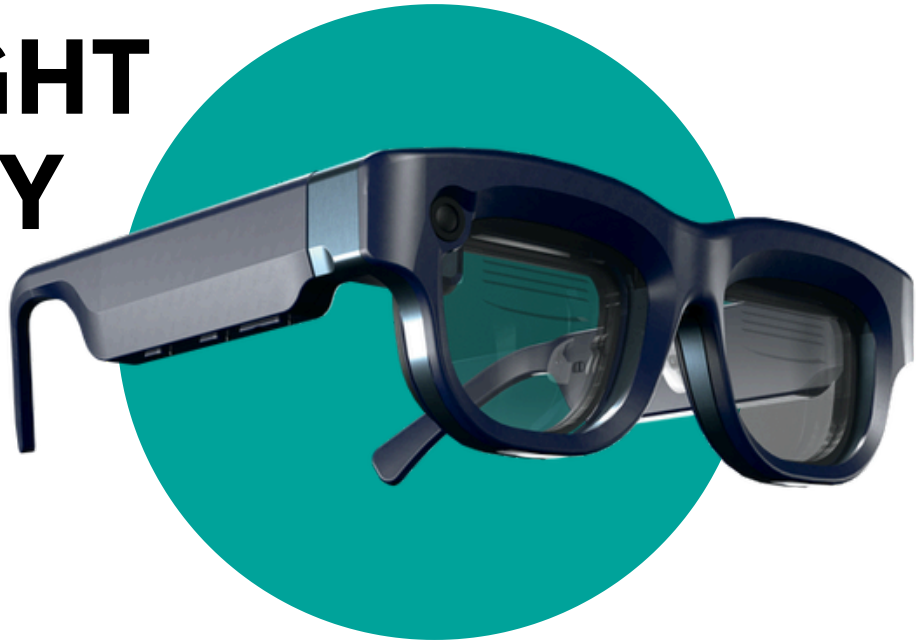

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Sponsors

Thank you to our event sponsors for their support in delivering the Retina UK Annual Conference 2026.

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

Delegate information

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

WiFi

Free WiFi is available for in-person delegates. Select **Edgbaston Park Hotel Guest WiFi 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/83459769312. 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.

Attendance certificate

If you have requested an attendance certificate, it will be issued one week after the Conference ends following verification of attendance.

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 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-annual-conf26**.

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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RETINA UK 50 YEARS
WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

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

RETINA UK
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Feedback

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

Understanding clinical trials and potential new therapies – what's in the pipeline?
A panel with representatives from biotechnology companies Sepul Bio, Alkeus and AAVantgarde.

10.55am

The participant perspective – reflections on taking part in clinical studies
Tina Garvey, Chief Executive, Retina UK. Professor Martin McKibbin, Consultant Ophthalmologist, University of Leeds. James Moore, who is living with inherited sight loss. Bhavna Tailor, Chief Executive, Stargardts Connected and Ethan Tailor, who is living with inherited sight loss.

11.40am

Break

12.10pm

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.

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1.00pm **Lunch**

1.50pm **Income to impact: the difference you can make**
Stories from some of our fantastic fundraisers. Jess Mortlock, Interim Director of Income Development.

2.20pm **Latest developments in stem cell-derived therapies**
Exciting updates from the world of stem cell-based therapies. Professor Robin Ali.

3.05pm **Quick break**

3.20pm **Meet today's speakers: your questions answered (in-person attendees only)**
Your chance to ask your questions to the speakers from throughout the day.

3.20pm **Retina UK staff panel: your questions answered (online attendees only)**
Kate Arkell, Research Director. Denise Rawden, Head of Information and Support. Mark Baxter, Information and Support Coordinator. Jess Mortlock, Interim Director of Income Development.

4.20pm **Close**

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CONFERENCE SPEAKERS

Professor Robin Ali
Professor of Human Molecular Genetics, King's College London

Professor Robin Ali is the Centre Director and Academic Lead in the Gene Therapy Vector Facility, King's College London. He is also Director of the Centre for Gene Therapy & Regenerative Medicine and Director of the NIHR Guy's and St Thomas' Biomedical Research Centre.

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.

Andrew Bolan
Patient Advocacy Director
Sepul Bio

Andrew (Andy) Bolan is Patient Advocacy Director at Sepul Bio, an innovative business unit of Laboratories Théa. For more than 14 years, he has worked to bring the patient and community perspective into healthcare and biopharmaceutical organisations, helping ensure that the experiences and priorities of people living with disease are reflected in decision-making.

Originally from the UK and now based in Amsterdam, Andy began his career with the Association of the British Pharmaceutical Industry (ABPI) before joining Teva, Biogen, ProQR Therapeutics, and now Théa. Throughout his career, he has partnered closely with patient organisations and community leaders across a range of disease areas, including neurological, respiratory, and inherited retinal diseases. Andy is passionate about building genuine partnerships with patient communities and believes that listening to and learning from lived experience is essential to improving healthcare, research, and treatment development.

Joseph Brennan
VP Patient Advocacy and Site Engagement

Joe has 30 years of healthcare and clinical trials experience. He currently leads Patient Advocacy and Site Engagement activities at AAVantgarde. In this role, Joe supports the integration of the patient experience and patient insights into AAVantgarde's clinical development programmes.

Joe is passionate about patient advocacy and the work AAVantgarde is doing to bring transformative therapies to patients living with IRDs.

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

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”.

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 an Honorary Fellowship from the University of Hertfordshire in 2024.

Anna Holloway

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.

Professor Martin McKibbin, Consultant Ophthalmologist, University of Leeds

Martin McKibbin is a very recently retired Consultant Ophthalmologist at St. James's University Hospital, Leeds. He held clinical and research interests in inherited retinal disease and has been chief and principal investigator for a number of interventional and observational studies.

James Moore

James, 26, 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.”

Denise Rawden
Head of Information and Support, Retina UK

Denise's background was in banking and customer management before moving to the charity sector in 2004 following the death of her husband in a road crash.

Denise helped to set up a new local charity supporting victims of road crashes and their families. As Volunteer Support Manager, Denise recruited, trained and supported a team of volunteers who themselves had been personally affected or bereaved through road collisions.

Denise joined Retina UK in 2013, managing and supporting the volunteer helpline team. In 2017, she moved into the role of Information and Support Manager. Denise is passionate about supporting our community by offering emotional support and providing accurate, clear information to help people make informed choices about their future. Denise's role involves developing and supporting services for both our community and the professionals who support them.

Rob Sears

Rob Sears is a human performance specialist, author, speaker and registered blind endurance athlete living with Choroideremia.

After decades of believing he had X-linked retinitis pigmentosa (RP), genetic testing at Moorfields Eye Hospital revealed his correct diagnosis, reinforcing his passion for raising awareness of the importance of genetic testing.

Through his speaking, coaching and social media, Rob shares his journey to educate, inspire and advocate for people living with inherited retinal conditions.

You can follow Rob on Instagram: @RobSearsOfficial.

Ben Shaberman
Patient Advocacy Consultant at Alkeus

Ben has worked in the inherited retinal disease community for more than two decades as a science communicator and patient advocate. He currently serves as a patient advocacy consultant, helping raise awareness of Alkeus's international Phase 3 NORTHSTAR clinical trial for gildeuretinol, an emerging oral therapy designed to slow the progression of Stargardt disease. Previously, he was VP of science communications at the Foundation Fighting Blindness. He launched his consulting business in January 2026.

Ben has released three books – Retina Boy (novel), Jerry's Vegan Women (short stories), and The Vegan Monologues (essays) – all published by Loyola University (Maryland). His fourth, The Kicker, will be published by Broken Tribe Press in summer 2026. His essays and commentaries have been carried by The Washington Post, the Baltimore Sun, Chicago Tribune, NPR, and a variety of other publications.

Ben earned an MA in writing from Johns Hopkins University, an MS in systems management from the University of Maryland, and a BS in computer information science from Cleveland State University.

He lives in Washington, DC.

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 Ethan 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 looking for practical information or emotional support, 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.

Helpline: 0300 111 4000 | helpline@RetinaUK.org.uk
Our Helpline team are here to support you. 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.

Events – RetinaUK.org.uk/info-events
We hold events online and face-to-face, including our Annual Conference and Professionals' Conference and our Webinar series.

Newsletters – RetinaUK.org.uk/resources
Sign up to receive the latest news from Retina UK, including our Look Forward magazine. Choose which format is best for you.

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)
- Podcast on Spotify
- 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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