

Retina UK **Annual CONFERENCE 2025**



Supporting people affected by inherited sight loss and investing in medical research to help make their challenges a thing of the past.





The Holiday Inn, Regent's Park, London



RetinaUK.org.uk/annual-conference

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 Annual Conference, in our 50th Anniversary year. Whether you have been involved with our charity from the very beginning, or you are new to us, we are delighted you have chosen to join us today.

I hope that all of our delegates have an enjoyable and thoughtprovoking day. We encourage participation both in-person and online so please ask questions. If you are with us in London, please visit our exhibitors and chat with Retina UK staff and our fantastic speakers. Thank you to them all for being with us today.

The theme today will demonstrate how far we have come in research and the search for a treatment. Retina UK will continue to be here for you, for as long as we are needed.

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

Enjoy the day.

Tina Garvey Chief Executive, Retina UK We need you: Donate to our **50**th **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 01280 815900 fundraising@RetinaUK.org.uk







Sponsors

Thank you to our event sponsors for their support in delivering the Retina UK Annual 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/annual-conference 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.

Online attendees - Zoom link

If you are joining us online, please use this link: https://us02web.zoom.us/j/82228411089. We will also make this link available on the home page of the Retina UK website for ease of navigation.

Questions

To allow us to include more speakers today, we will not be taking questions at the end of each session.

- If you are joining us in London today you can meet and ask questions of our speakers in person from 3.00pm.
- Online delegates can ask Retina UK staff questions throughout the day using the Q&A button on Zoom.
 Professor Julie Silvestri will answer medical questions during her session. Please use the Q&A button.

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.

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-conf25.

Recordings

Recordings of all of the Conference presentations, including Professor Silvestri's session, will be sent to both online and inperson delegates during the week following the Conference.

DOUBLE YOUR DONATION: 2 - 9 DECEMBER!

During our 50th 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**.

"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."



SAVE THE DATE!





RETINA UK LOTTERY

Join our Lottery and you could win £25,000 every week - for just £1 a line!
Sign up today:



DON'T DELAY, PLAY 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 (<u>navilens.com/en</u>).

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

9.30am

Registration opens

Networking 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 and Professor John Marshall MBE, Trustee, 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

10.50am

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 (in-person delegates only)

Ask the expert: Professor Julie Silvestri (online delegates only)

4.00pm

Close

Retina UK Day 2025

Come together to support
Retina UK on World Sight Day
and organise your own
fundraiser to help us raise
much-needed funds and
awareness during our 50th
anniversary year.





Support our vital work!



#RetinaUKDay

Text **RETINAUKDAY** to **70450** to donate **£5** during our 50th anniversary year.

RetinaUK.org.uk/retina-uk-day-2025

Sign up here:





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.



Professor John Marshall MBE Trustee, Retina UK

Prof John Marshall is the Frost Professor of Ophthalmology at the Institute of Ophthalmology at University College London.

He is Emeritus Professor of Ophthalmology at Kings College London; Honorary Distinguished Professor, University of Cardiff; Honorary Professor the City University and Honorary Professor Glasgow Caledonian University. John is one of our longest serving trustees.

His eye-related research over the past 40 years has been wide ranging but has concentrated on the mechanisms underlying age-related, diabetic, and inherited retinal disease and the development of lasers for use in ophthalmic diagnosis and surgery. This led to the development of the Excimer laser for the correction of myopia as well as some 300 research papers and many books. John edits a number of international journals and has been awarded numerous medals for research.

He has been a staunch supporter of the organisation since its inception in the mid-1970s.



Kate Arkell Research Development Manager, 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 as Research Development Manager.

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.



Professor Michel Michaelides,
Professor of Ophthalmology,
University College London and
Consultant Ophthalmic Surgeon,
Moorfields Eye Hospital

Michel Michaelides is a Consultant Ophthalmologist at Moorfields Eye Hospital in the departments of Medical Retina, Inherited Eye Disease and Paediatric Ophthalmology; and is a Professor of Ophthalmology at the UCL Institute of Ophthalmology.

His clinical and research interests include inherited eye disease in adults and children; with over 500 peer-reviewed publications and 50 book chapters. He is actively involved in retinal clinical trials investigating novel therapies, being a principal investigator in 15 on-going clinical studies and trials.



Professor Jane Sowden, Professor of Developmental Biology and Genetics at University College London Great Ormond Street Institute of Child Health

Jane Sowden has been Professor in Developmental Biology and Genetics at UCL Great Ormond Street Institute of Child Health since 2011 and leads the Eye Development and Repair Research Group. Since 2022 she has been Theme Lead of the Tissue Engineering and Regenerative Medicine Theme in the GOSH Biomedical Research Centre.

She read Biochemistry at Oxford University and was awarded a PhD in Molecular Genetics at UCL, followed by postdoctoral training at the MRC Human Biochemical Genetics Unit.

She has published widely on retinal development, genetic causes of congenital eye defects and childhood blindness, as well as the development of stem cell therapies for retinal disease, including landmark studies demonstrating the feasibility of retinal repair by cell transplantation. Her current research aims to increase knowledge of genetic causes of childhood eye conditions and to develop novel stem cell and gene-based therapies for inherited causes of childhood blindness and conditions causing deaf blindness.



Christopher Patnoe, Head of EMEA Accessibility and Disability Innovation at Google

Christopher Patnoe is the Head of Europe, the Middle East and Africa (EMEA) Accessibility and Disability Innovation at Google. He leads Google's efforts around the accessibility of product, policy and partnerships across EMEA - with a particular focus on emerging markets. He has almost 30 years experience in tech working at companies like Apple, Sony Ericsson and Disney where he's built hardware, software, games, and services. He is the chair for the Immersive Captions Community Group with the W3C, is the Accessibility Working Group Co-Chair for the XR Association, and is an independent member of the board for SCOPE. Christopher has a degree in Music from UC Berkeley.



James Clarke, Head of Income Generation, Retina UK

Since a diagnosis of retinitis pigmentosa in September 2015, James Clarke has been a long-term voluntary fundraiser for Retina UK, before joining the staff team in May 2023. In his role, he oversees the fundraising strategy for the charity and is responsible for generating the income that we need to make a vital impact for our community.



Professor Julie Silvestri, Clinical Director for Ophthalmic Services at the Belfast Health & Social Care Trust

Julie Silvestri is Clinical Director for Ophthalmic Services at the Belfast Health & Social Care Trust, Honorary Professor at the Centre Public Health at Queen's University Belfast and Co-Lead for the NI Clinical Research Network.

Julie's programme of research focuses on genetic predisposition and causative genetic variants in ophthalmic diseases with emphasis on age-related macular degeneration (AMD) and inherited retinal disorders and on implantable low vision devices. She has collaborated internationally with investigators in the USA, Ireland, Ghana and Israel and nationally with a number of research groups.



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.

Discover Wellbeing - 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.

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 <u>Spotify</u>, Apple and Google podcasts,
- Facebook groups:
 - o <u>facebook.com/groups/retinauklocal</u>
 - facebook.com/groups/therpgroup

Sign up to receive our information RetinaUK.org.uk/mailing-list, email 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



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



Touch screen and keypad



Vocalised user interface



Multi-format audio playback



Magnifier with filters

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





Retina UK

Whiteleaf Business Centre 11 Little Balmer Buckingham MK18 1TF

01280 821334 info@RetinaUK.org.uk RetinaUK.org.uk

Helpline: 0300 111 4000 | Helpline@RetinaUK.org.uk

Retina UK is a Charitable Incorporated Organisation (CIO), registered in England and Wales. Registered charity number 1153851.









