



# ANNUAL CONFERENCE

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UNIVERSITY OF  
WESTMINSTER, LONDON

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**24 JUNE 2023**

# WELCOME

Welcome to the 46th Retina UK Annual Conference where we come together for knowledge sharing, support, and empowerment within the inherited sight loss community.

Whether you are attending online or in person this year, thank you for joining us. We have a packed programme for you today.

This conference aims to foster a collaborative environment, bridging the gap between cutting-edge research and the everyday lives of those living with inherited sight loss.

Throughout our conference, attendees will have the opportunity to engage in enriching discussions, have their questions answered, and learn from esteemed experts in the field. We will delve into topics such as emerging gene therapies, assistive technologies, and psychological wellbeing for individuals and families affected by inherited sight loss.

Moreover, this conference goes beyond scientific exploration. It is a platform for personal stories and shared experiences, promoting a sense of community and solidarity among attendees.

If you're joining us in person, please visit our exhibitors, chat with the team and to other delegates and families.

We are very grateful to all of our sponsors and exhibitors for their support, including our headline sponsor Janssen.

Enjoy the day.



Tina Garvey  
Chief Executive, Retina UK

# SPONSORS

Thank you to our event sponsors for their support in delivering the Retina UK Annual Conference 2023.



Janssen UK has provided a grant towards the costs of this conference and has had no input into the agenda

# DELEGATES' INFORMATION

## 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.

## Social Media

We'll be tweeting throughout the day on our Twitter feed @RetinaUK – if you're sharing thoughts about the conference on social media, you can use the hashtag #RetinaUKConf. We'll also be uploading photos and updates on our Facebook, LinkedIn and Instagram pages.

## Feedback

Your views are important to us, please take a few minutes to share your feedback after the event by completing this form: **[RetinaUKorg.uk/feedback-conference23](https://RetinaUKorg.uk/feedback-conference23)**.

We hope you enjoy the conference today. 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, and 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.



# EVENT PROGRAMME

24 • JUNE • 2023

10.00am	<b>Welcome and housekeeping</b>
10.05am	<b>Introduction to the day</b> Tina Garvey, Retina UK
10.15am	<b>Stronger together: working in partnership to achieve our aims</b> Rob Cooper, RNIB Martin Hills Kate Downey, Janssen UK James Clarke
11.25am	<b>Tomorrow's world: The technology of the future</b> Glenn Tookey, Sight and Sound Technology Dr Robert Quinn, Imperial College London
12.00pm	<b>Lunch</b>

# EVENT PROGRAMME

24 • JUNE • 2023

1.05pm	<p><b>Retina UK strategic vision of treatment for all</b></p> <p><b>Gene therapy - augmentation, editing and silencing</b> Professor Tara Moore, Ulster University</p> <p><b>The potential of stem cell treatments</b> Professor Lyle Armstrong, Newcastle University</p> <p><b>Practical example of gene therapy</b> Mr Kanmin Xue, University of Oxford, Oxford Eye Hospital</p> <p><b>Practical example of the role of synthetic implants</b> Professor Paulo Stanga, The Retina Clinic, London</p>
2.35pm	<b>Break</b>
2.55pm	<p><b>Research / Medical Q&amp;A</b></p> <p>Put your burning questions to our panel of seven leading experts in the field of inherited sight loss and treatment development.</p> <p>Professor Tara Moore, Professor Lyle Armstrong, Mr Kanmin Xue, Professor Paulo Stanga, Professor John Marshall, Dr Elizabeth Graham, Mr Simon Keightley</p>
3.55pm	<b>Closing remarks</b>
4.00pm	<b>Close</b>



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

Tina Garvey is Chief Executive at Retina UK. Since joining the charity, in August 2015, the organisation has grown so the team can provide even more information and support services, and work toward funding more 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. Tina has raised the profile of Retina UK, not only in the charity sector, but also with professionals, individuals and families close to inherited sight loss, creating tangible benefits to those the charity represents. 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; before becoming the Chief Executive at Retina UK Tina ran the East and North Herts NHS Hospitals' Charities for over five years and before that held senior fundraising roles in national charities. Tina has a BSc in Science and Social Sciences, a postgraduate diploma in Marketing, an MSc in Leadership and Management in Public Services and is currently working toward a Masters in Law.



## **Rob Cooper, Strategic Engagement Lead, RNIB**

Rob has over 22 years' experience of working within the health and social care landscape. During this time he has forged strong strategic alliances between the NHS, Social Care Services and third sector charities. He is dedicated to improving health literacy to ensure patients are informed and empowered to actively participate in their health care. He is the architect and co-creator of the COPD Patient Pathway, Pathway to Independence Model, Seven Steps Model and the joint author of the Greater Manchester Community Sight Loss Strategy, all of which is driven by lived experiences and co-produced with patients. He is currently working alongside NHS England and the Eye Care Recovery and Transformation programme and leading RNIB's ambition to co-create an eyecare support pathway.





## Martin Hills

Martin is part of the Retina UK Email Helpline Team. He started volunteering in this role in 2014 and has been the Administrator since 2017.

He was diagnosed with retinitis pigmentosa (RP) in 2001 (aged 49), certified as Partially Sighted in 2002 and as Severely Sight Impaired in 2017. His eyesight is slowly deteriorating but he still has reasonable central vision. He is a Symbol Cane user.

His father and one of his children have also been diagnosed with RP along with relatives in four generations of his wider family.

He undertook genetic counselling and testing in 2014 which confirmed autosomal dominant RP.

He and several members of his wider family have participated in the UK's 100,000 Genome Project but the causative gene for his condition has not yet been identified.

Martin worked as a Chartered Civil Engineer until he retired (working in the UK and abroad).



## **Kate Downey, Patient Engagement Lead, Janssen UK**

Kate leads the Janssen UK Patient Engagement and Advocacy team and has been passionate about her work with patient organisations, patients and caregivers since moving into the field of patient engagement in 2010. Kate works with patient organisations who support and advocate for people with a range of conditions including solid tumour and blood cancers, autoimmune and immune mediated conditions, mental health, pulmonary hypertension and inherited sight conditions. Committed to championing the voices and needs of patients, Kate focuses on working to better understand their lived experiences, partnering with different groups to positively impact, and ultimately improve the lives of patients.

Kate has a degree in Medicinal Chemistry from University College London and, prior to being dedicated to patient engagement, spent 15 years in a variety of in-house pharmaceutical and agency roles ranging from sales and training to professional relations, medical education and communications.



## James Clarke

Spurred on by a diagnosis of retinitis pigmentosa, James decided to turn his attention to making a difference and over the past eight years has raised over £105,000 for Retina UK as a third party fundraiser through various challenge events and the annual award-winning talent show, Worksop's Got Talent. A passion for events and fundraising followed, alongside seven awards for his events. James recently joined Retina UK as our new Events & Community Fundraising Manager.



## **Glenn Tookey, Chief Executive Officer, Sight and Sound Technology**

Glenn is the Chief Executive Officer at Sight and Sound Technology, a role he has held since 2008. Sight and Sound are the UK's leading provider of services to the blind and visually impaired and his role has led him into many relationships with inventors and developers of new technology in the field of low vision. A key part of his role is to find technology that will change the lives of people with sight loss and to bring it in an affordable and supportable fashion to the UK market.

Glenn has always been involved in technology and development. From his early days at BT where he led research and development projects, through the internet revolution at the data hosting provider Telecity and then to InTechnology to where he built one of the UK's first voice over IP architectures.



## **Dr Robert Quinn, CEO, MakeSense Technology**

Robert Quinn is the founder and CEO of MakeSense Technology Limited, a technology spinout from Imperial College London. MakeSense is developing 'sensory substitution' technology for people with visual impairments that can pass visual information to the brain through other sensory modalities, such as touch and sound. Robert graduated with a PhD in Mechanical Engineering from Imperial College London in 2021 and is honorarily affiliated with Imperial College's Intelligent Systems and Networks Research Group.



**Professor Tara Moore,  
Professor of Personalised  
Medicine, Ulster University.  
Chief Research and  
Development Officer, Avellino  
Labs in Menlo Park, San  
Francisco**

Tara Moore, Professor of Personalised Medicine, concurrently holds a chair at Ulster University in Northern Ireland and is Chief Research and Development Officer for Avellino Labs in Menlo Park San Francisco USA.

Tara has a wealth of experience of working in universities and industrial laboratories focusing on development of partner diagnostics and treatment for genetic eye disease.

Tara's research team concentrates on identifying genes which cause disease and in developing gene editing and gene silencing treatments for autosomal dominantly inherited eye diseases. Her work is disseminated worldwide through her contribution to guest lectures and workshops and internationally co-authored peer reviewed publications. Tara has contributed to numerous text books and authored over 120 peer reviewed publications in high impact peer reviewed journals reflecting internationally competitive research of high quality.

Tara is a Fellow of Royal Society of Biology, UK, Royal Society of Arts, UK, Royal Society of Medicine, UK, Senior Associate of Royal Society of Medicine and Honorary Fellow of Royal College of Physicians (London) FRCP, FFLM. She is also expert reviewer for numerous peer reviewed journals and editor / academic editor for a number of the top peer reviewed journals.



## **Professor Lyle Armstrong, Professor in Cellular Reprogramming, Institute of Genetic Medicine, Newcastle University**

Professor Lyle Armstrong is Professor in Cellular Reprogramming at the Institute of Genetic Medicine in Newcastle University. He studied chemistry at the Universities of Sheffield and Northumbria and was awarded a PhD in Physical Organic Chemistry in 1992. He later re-trained in Molecular and Cell Biology at Durham University. He founded a contract research organisation developing diagnostic systems to identify and enumerate bacteria in biological fluids. Prof Armstrong's research record is exemplary, having been involved in the programme leading to the derivation of some of the UK's first human embryonic stem cell lines, development of the world's first cloned human embryos and establishment of one of the first groups to use Induced Pluripotent Stem Cell technology in the UK. The Armstrong research group has received funding exceeding £10 million over the last 10 years leading to 85 publications and supervision of 14 past and ongoing PhD students. Prof Armstrong is also Founder and Chief Scientific Officer of the spin-out company Newcells Biotech Ltd which was created to commercialise the research outputs from the Armstrong / Lako Pluripotent Stem Cell research laboratories in the Institute of Genomic Medicine. The concept behind the company is to establish and commercialise model systems for efficacy and toxicity testing in drug discovery programmes within the pharmaceutical industry.



## **Mr Kanmin Xue, Consultant Vitreo-retinal Surgeon, John Radcliffe Hospital. Wellcome Trust Clinician Scientist Fellow, University of Oxford**

Mr Xue completed undergraduate medical training at Brasenose College Oxford (with the top first-class – Martin Wronker Prize in Medicine) and clinical training at Trinity College Cambridge as part of an MB-PhD programme. Following a residency in London and completion of ophthalmology specialist training in Oxford / Thames Valley Deanery, he undertook the prestigious Vitreo-retinal Fellowship at the Royal Victorian Eye & Ear Hospital in Melbourne, Australia. He was the NIHR Academic Clinical Lecturer in Oxford, leading research and clinical trials of retinal gene therapy and robotic eye surgery.

Clinically, he looks after patients with general ophthalmic conditions, cataracts, and offers sub-specialist expertise in retinal diseases. He supervises and trains surgeons in cataract surgery (including dealing with complications) and the full spectrum of vitreo-retinal surgery.

Mr Xue is the recipient of numerous awards, including the Ruskell Medal (Worshipful Company of Spectacle Makers), Ian Fraser Cup, Luigi Barca Award, and Martin Wronker Prize in Medicine.





**Professor Paulo Stanga,  
Director, Consultant Vitreoretinal  
and Cataract Surgeon, The Retina  
Clinic, London. Professor of  
Ophthalmology, Institute of  
Ophthalmology, University College  
London**

Paulo Stanga is a Consultant Vitreoretinal & Cataract Surgeon at The Retina Clinic London, and Professor of Ophthalmology at Institute of Ophthalmology / University College London (UCL). He has over 30 years in Ophthalmology, including 21 years in the NHS. Prof Stanga has been a Principal Investigator on industry-sponsored trials and Scientific Advisor to commercial companies that develop pharmacological / surgical therapies and diagnostic / therapeutic equipment.

He introduced Optical Coherence Tomography (OCT) into clinical settings in 1998, and pioneered Ultra-Widefield Imaging and the Argus II Electronic Retinal Implant for Artificial Vision in retinitis pigmentosa.

Prof Stanga is a former UK Chief Investigator and local Principal Investigator (PI) and Surgeon in a Gene Therapy Study in RP (RPGR); results published in Nature Medicine (2020).

He has received several international accolades, amongst others; Achievement Award / American Academy of Ophthalmology (AAO); listed in The Ophthalmologist 2023 Power List of the most influential and inspirational people in Ophthalmology; Liveryman / The Worshipful Company of Spectacle Makers and Freeman / City of London.



## **Professor John Marshall MBE Trustee, Retina UK**

Professor 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 at Retina UK.

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 has 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.



## **Dr Elizabeth Graham Trustee, Retina UK**

Dr Graham undertook research into the basic mechanisms of retinal vasculitis; inflammation of the blood vessels in the retina. An important cause of poor vision in patients with uveitis is inflammation of the uveal tract.

Inflammation of the eye has remained her chief clinical interest and in particular the optimum management of patients with this devastating disease.

She has written over 150 peer reviewed publications and has contributed 10 chapters to text books and given five eponymous lectures.

She was appointed consultant to the Medical Eye Unit at St Thomas in 1988 and was also one of four eye consultants at the National Hospital for Neurology and Neurosurgery and looked after children with inflammation of the eye associated with arthritis at Great Ormond Street Hospital. She is a well-respected national and international authority on the management of patients with uveitis.

She has been responsible for developing a training programme for medical ophthalmologists in the United Kingdom and has had a pivotal role in developing postgraduate examinations for ophthalmologists as well as working for the General Medical Council as a performance assessor.



## **Mr Simon Keightley, Trustee, Retina UK**

Simon spent 40 years as a Consultant Ophthalmic Surgeon at the North Hampshire Hospital in Basingstoke.

He specialised in the management of retinal diseases, especially diabetic retinopathy and age-related macular degeneration, the commonest causes of sight threatening problems. In addition, he spent many years as an examiner for the Royal College of Ophthalmologists, eventually becoming Senior Examiner and chair of the College Examinations Committee. He was also Director for Examinations of the International Council of Ophthalmology, organising the assessment of ophthalmologists across the world as well as working as a performance assessor for the General Medical Council.

Simon is also interested in vision and driving, having worked as chair for the Ministry of Transport Medical Advisory Committee for Vision and Driving. He is well aware of the impact the loss of a driving licence can have for people affected with sight-threatening diseases. He also worked for a while for the International Paralympic Committee in assessing visually impaired competitors for their individual classification group.

**The formal business matters of the charity will be discussed at the Annual General Meeting. Members are encouraged to attend. It will start at 4.00pm.**

Welcome

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Apologies

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Approval of the minutes of the previous AGM (result of online voting)

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Presentation of the annual report and accounts for the year ended 31 December 2022

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Adoption of the Annual Report and Accounts for 2022 (result of online voting)

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The appointment of the auditors (result of online voting)

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Presentation of Retina UK activity in 2022 and 2023 overview – Chairman Martin Kirkup

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The appointment of trustees (result of online voting)

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Any other business

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
- Wall charger
- 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 Intium £542.50

- Smartphone
- USB-C cable
- Wall charger
- Stereo headphones
- NFC tags (x5)
- SIM extraction tool
- Inductive charger

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# RETINA UK

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

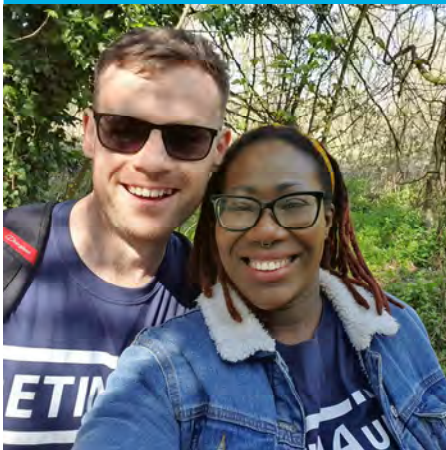
Join #TeamRetinaUK in 2023/2024 and help support people affected by inherited sight loss to lead better lives today and accelerate the search for treatments for the future. We are here to support you every step of the way.



## RUN

First time runner or seasoned pro? Join us for a top race including the London Landmarks Half Marathon, 2024 TCS London Marathon, Great North Run, Royal Parks Half and more!

[RetinaUK.org.uk/run](https://RetinaUK.org.uk/run)



## WALK

Whether you fancy coastal paths or riverside rambles, sign up to a 25, 50 or 100km Ultra Challenge Trek:

[RetinaUK.org.uk/trek](https://RetinaUK.org.uk/trek)



## JUMP

Strapped to your expert instructor, jump from a plane at 10,000ft and freefall at speeds of up to 120mph!

[RetinaUK.org.uk/skydive](https://RetinaUK.org.uk/skydive)



Retina UK is a Charitable Incorporated Organisation, registered charity no. 1153851



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