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PROFESSIONALS' CONFERENCE

UNIVERSITY OF
WESTMINSTER, LONDON

23 JUNE 2023

WELCOME

Welcome to the fourth Retina UK Professional Conference where we come together to support you in your work with the inherited sight loss community. Working in partnership we aim to equip you with the knowledge you need to make the biggest difference for your service users. We are pleased to offer CPD accreditation for today's Conference. It is available for all attendees.

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

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

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

Enjoy the day.

A handwritten signature in black ink, appearing to read 'Tina Garvey', with a large, stylized initial 'T'.

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 #RetinaUKProfConf. 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 the form:

RetinaUKorg.uk/feedback-prof-conf23.

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** or visit the Retina UK stand in the exhibition area.



EVENT PROGRAMME

23 • JUNE • 2023

10.00am	Welcome and housekeeping
10.05am	Introduction to the day
10.15am	Experience of diagnosis / points of impact within the sight loss community Dr Jasleen Jolly, Anglia Ruskin University
10.35am	Sight loss pathway: A collaborative approach Rob Cooper, RNIB
11.00am	Break
11.20am	Learning from lived experience: the wider family's perspective People living with inherited sight loss, their parents and partners, share experiences from their sight loss journeys. Panel discussion facilitated by Paula McGrath, Director of Development, Retina UK

EVENT PROGRAMME

23 • JUNE • 2023

12.20pm	Lunch
1.20pm	Difficult conversations and breaking bad news Professor Susan Downes, Oxford University Hospitals Dr Amanda J Salisbury, Oxford University Hospitals
2.20pm	Break
2.40pm	Research update An overview of the latest progress in development of therapies for inherited sight loss. Kate Arkell, Retina UK
3.10pm	Retina UK Professionals' project How we can support you and families affected by inherited sight loss Matthew Carr, Retina UK
3.25pm	Closing remarks
3.30pm	Close



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.



**Dr Jasleen Jolly,
Associate Professor at
the Vision and Eye
Research Institute,
Anglia Ruskin University**

Dr Jasleen Jolly is an Associate Professor at the Vision and Eye Research Institute, ARU. She completed a PhD in clinical neuroscience from the University of Oxford, whilst working on the gene therapy trials. Her work combines ophthalmology, optometry, neuroscience, psychology, and other disciplines to probe low vision from different points of view.



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.



Paula McGrath, Director of Development, Retina UK

Paula is Director of Development at Retina UK.

Paula joined the health charity sector 17 years ago, 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.

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

Paula is also a Trustee of Harry's Rainbow, a charity that provides support to children bereaved of a parent or sibling.



**Dr Amanda J
Salisbury, MA DM
MRCP FRCR,
Oxford University
Hospitals NHS
Foundation Trust**

Amanda Salisbury is a Clinical Oncologist, a Consultant at the Oxford University Hospitals NHS Foundation Trust with a practice in head and neck cancer and 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.

She is a Nuffield Lecturer in Clinical Medicine to Lincoln College, Oxford. She is also an examiner, and 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 a number of 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.



**Professor Susan
Downes,
Consultant, Oxford Eye
Hospital, Oxford
University Hospitals
University NHS
Foundation Trust**

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.

Over the last few years, she has become involved in breaking bad news in eye disease teaching sessions for Ophthalmologists and Allied health professionals. Her main clinical and research interests include inherited retinal dystrophies (completing an MSc in human genomics in 2018), age related macular degeneration and other macular diseases.



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, where she 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 coming to 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 the Retina UK community's engagement with research.



Matthew Carr, Information and Support Manager, Retina UK

Matthew has worked in the sight loss charity sector for over 10 years. He leads on events, webinars and supporting the professionals' community at Retina UK. He previously worked for both RNIB and the Thomas Pocklington Trust where he was responsible for the delivery of the England Vision Strategy. Before moving to the charity sector, Matthew worked in the Police Service specialising in roads policing and firearms. Matthew has lived experience of inherited sight loss with retinitis pigmentosa.

VIRTUAL VISION
REAL IMPAIRMENT

Virtual Reality Visual Impairment Training

Our CPD-certified training has been designed to help professionals, caregivers, medical staff, and families that support people with visual impairment. By combining cutting-edge technology with professionally qualified trainers, we aim to help organisations:

- Promote understanding and acceptance of visual impairments within the workforce.
- Understand complex medical terminology surrounding visual impairment.
- Develop strategies for supporting a broad spectrum of visually impaired clientele.
- Increase working environment accessibility for visually impaired employees and customers.
- Enhance reputation and brand image.



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RETINA UK

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

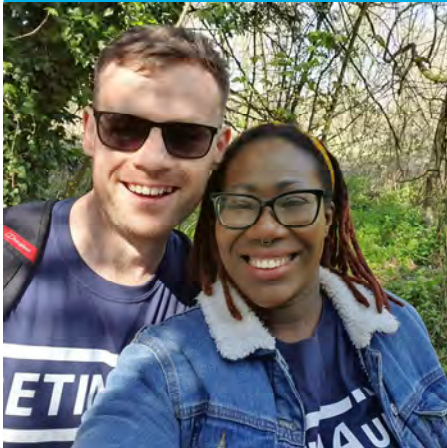
Join #TeamRetinaUK in 2023/2024 and help support people affected by inherited sight loss to lead better lives today and accelerate the search for treatments for the future. We are here to support you every step of the way.



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



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RetinaUK.org.uk/skydive



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Retina UK

Wharf House, Stratford Road,
Buckingham, MK18 1TD

01280 821334

info@RetinaUK.org.uk

RetinaUK.org.uk

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

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