



Retina UK

Annual

CONFERENCE

Saturday 28 September 2024

The Pendulum Hotel,
Manchester

Welcome

Welcome to the 47th Retina UK Annual Conference where we come together to share knowledge, offer support, and empower the inherited sight loss community.

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

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.

Today you will have the opportunity to engage in enriching discussions, have your questions answered, and learn from esteemed experts in the field. Importantly, it is also a time to share lived experiences, promoting a sense of community. If you're joining us in person, please visit our exhibitors, chat with the Retina UK team, our speakers and to other families.

We are very grateful to all of our sponsors and exhibitors, including our headline sponsor Johnson & Johnson.

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 2024.

Johnson & Johnson

This conference is part funded through a sponsorship from Johnson & Johnson who have had no control or influence over the agenda or content.



Retina UK Day 2024

Come together to support **Retina UK** on World Sight Day and organise your own fundraiser to help us raise funds and awareness for those who are living with inherited sight loss.



Thursday,
10
October
2024

#RetinaUKDay

Text **RETINAUKDAY** TO 70450 to donate £5.

RetinaUK.org.uk/retina-uk-day-2024

Retina UK is a Charitable Incorporated Organisation (CIO), registered charity number 1153851

RETINA UK
Day 2024



SIGN UP HERE:



Delegate information

Wifi

Free wifi is available for in person delegates. Join at Pendulum Guest.

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 posting throughout the day on our X 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 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 here: **RetinaUKorg.uk/feedback-annual-conf24**.

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, 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.

NaviLens

This year we are trialling the use of NaviLens for signage throughout the conference and the programme. It is free and easy to use.

To download head to the NaviLens website: navilens.com/en.

At the bottom of this page go to “Free download available” and choose either Google Play (Android) or App store (Apple).

When download is complete, simply open the app, and start using NaviLens!

The process is simple, when the app is open, hold your phone near the Navilens icon. The camera will capture the tag and provide an audio description about what the icon represents.

Listen to the programme!





Programme

- 9:30 am** Registration and networking
- 10.00 am** Welcome, *Tina Garvey (Retina UK)*
- 10.15 am** **The Eye Care Support Pathway and what it means for you**
How this new guide and Retina UK can help you to access information, support and advice to help you live your best life.
Helen Doyle (RNIB), Denise Rawden (Retina UK), Bhavini Makwana (BAME Vision)
- 11.00 am** Break
- 11.30 am** **Harnessing the power of peer-to-peer support**
Our panel of lived experience volunteers and service users explain the positive impact peer-to-peer support has had on their lives.
Paula McGrath (Retina UK) leads a panel session
- 12.30 pm** Lunch



Programme

- 1.15 pm** **Supporting the next generation of research leaders: a discussion with Retina UK-funded PhD students**
Our three new PhD student grantees, funded by donations, will share their findings. *Chloe Brotherton, Hassina Zeriri, Gabriel Velichkova, Kate Arkell (Retina UK)*
- 2.00 pm** Short comfort break
- 2:15 pm** **Progress at the forefront of Inherited Sight Loss research**
An overview of the latest promising research.
Professor Graeme Black
- 3.00 pm** Break
- 3.30 pm** **Research Q&A**
Professor Graeme Black, Dr Panagiotis Sergouniotis, Kate Arkell (Retina UK)
- 4.00 pm** Close



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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. Tina 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 has recently been awarded a Honorary Fellowship from the University of Hertfordshire.



Paula McGrath
Deputy Chief Executive, Retina UK

Paula is Deputy Chief Executive at Retina UK. Paula joined the health charity sector 19 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 Retina UK's first 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.



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.

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Helen Doyle **Strategic Engagement Manager, RNIB**

Helen is Strategic Engagement Manager to the NHS at RNIB.

Her background is in health research and she has a number of publications across health policy and more recently in visual impairment and the third sector.

She has worked in the eye care and sight loss sector for 17 years.

Her previous role was as a research and insight manager where she focused on evidencing the need for support for people with eye care needs.

In her current role at RNIB she has been working on the development of the Eye Care Support Pathway collaborating across the sector to ensure people with eye care needs and their support requirements are central.



Kate Arkell
Research Development Manager

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.



Professor Graeme Black

Graeme is Professor of Genetics and Ophthalmology at Central Manchester University Hospitals NHS Foundation Trust. During training he undertook at DPhil - funded by Retina UK - with Professor Ian Craig at the University of Oxford, studying the genetics of X-linked inherited eye disease (IED).

Graeme's major research interest is the investigation of genetic disorders associated with visual disability. His aims are to improve the diagnosis and treatment of such conditions. Alongside the discovery of the genetic causes of inherited retinal disorders, this includes participation in treatment / gene therapy trials. He helped to bring together the team that now delivers of gene therapy for RPE65 in Manchester in 2019.

As part of what is now a large team of clinicians and scientists, Graeme leads and supports the busy clinical service in the North West. With initial funding provided by the Department of Health and Retina UK, his team developed a genetic testing service for inherited retinal disease. Graeme continues to oversee the scientific team providing accredited genomic testing for IED patients.



Chloe Brotherton, PhD Student

Chloe completed both her Bachelor's degree in Genetics BSc (Hons) and Master's degree in Medical Genetics and Genomics MSc (Med Sci) at the University of Glasgow from 2018 to 2023. During this time, she conducted research projects under the supervision of Professor Tom Van Agtmael and Professor Joanna Wilson. Her research with Professor Van Agtmael focused on investigating the role of collagen type-IV in intracerebral haemorrhages using RNA sequencing analysis. With Professor Wilson, she explored how the location of Epstein-Barr virus insertion may drive lymphoma in mice.

Chloe is now undertaking a PhD under the supervision of Dr Roly Megaw hoping to decipher the role of RPGR in photoreceptor disc formation with a particular focus on its role in cones. This project is jointly funded by Retina UK and the Macula Society. In her spare time Chloe enjoys hiking in the Scottish Highlands and wild swimming.



Hassina Zeriri, PhD Student

Hassina Zeriri is a researcher in the field of genetics, currently embarking on a PhD program at University College London (UCL) funded by Retina UK. Her research focuses on the impact of photopsia and photophobia conditions on Stargardt disease patients, motivated by her own experience.

Most recently, she served as a visiting researcher at the UCL Institute of Ophthalmology, where she worked in the Vision Perception Repair (VPR) Lab under Dr Matteo Rizzi. Prior to this, Hassina was a research assistant at Sidra Medicine's Human Genetics Department and a Research Specialist at Weill Cornell Medicine - Qatar, where she worked on various genetic medicine projects.

Hassina's technical skills include cell culture, DNA extraction, and various research methodologies. She has contributed to significant publications, including a study on whole-exome sequencing identifying common and rare variant metabolic QTLs in a Middle Eastern population, published in *Nature*.



Gabriel Velichkova, PhD Student

Gabriel graduated from the University of Manchester (UoM) with an MSci Genetics degree. Her Masters project in Professor Brenan's laboratory examined the interactions between the Wnt and Notch 4 signalling pathways at transcriptional level.

Following graduation, Gabriel worked as a Research Technician at the UoM. Later, she worked in Professor Santos laboratory at the Francis Crick Institute, where she used cloning strategies and CRISPR-Cas9 technologies to generate tools to help study how CDK 1, 2, and 4/6 activity change during the early stages of hESCs differentiation.

Gabriel then went to the University of Heidelberg where she used hiPSCs to study endothelial-cardiomyocytes (CMs) interactions and the role of shear stress mechanical forces on CMs differentiation, maturation, and function. Gabriel is currently working on an MPhil/PhD project that aims to examine if prime editing is a viable therapeutic approach for Stargardt's disease caused by ABCA4 c.5461-10T>C variant under the supervision of Professor Jacqui van der Spuy and Professor Michael Cheetham at University College London.



Dr Panagiotis Sergouniotis

Dr Panos Sergouniotis is a Wellcome Clinician Scientist at the University of Manchester and an Honorary Consultant in Ophthalmology and Genetics at the Manchester Royal Eye Hospital and the Manchester Centre for Genomic Medicine

Panos studied Medicine at the University of Athens and received a PhD in Ophthalmic Genetics from the UCL-Moorfields Institute of Ophthalmology. He subsequently joined the University of Manchester where he leads a multidisciplinary research group working at the interface of genomics, stem cell biology and clinical ophthalmology. He has published extensively in the field of vision research (including a textbook on 'Clinical Ophthalmic Genetics and Genomics' and more than 100 papers) and has received multiple awards (including a Wellcome Trust Career Development Fellowship).

Panos has set up a Paediatric Ophthalmic Genetic service in Manchester and has a long-standing clinical interest in inherited retinal conditions. His ultimate aim is to provide a framework for preserving and restoring high-resolution detailed vision.



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Notes

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