



# Retina UK Professionals' CONFERENCE

Friday 27 September 2024

The Pendulum Hotel,  
Manchester

# Welcome

Welcome to the fifth Retina UK Professionals' 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 families affected by inherited sight loss, including how Retina UK can support you and your clients. 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, 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 Retina UK team and to other delegates.

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





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# 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:

**[RetinaUK.org.uk/feedback-prof-conf24](https://RetinaUK.org.uk/feedback-prof-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](https://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](https://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** **Working together to deliver the Eye Care Support Pathway**  
How we can enable families to get the information, support and advice they need to live their best lives at all stages of their sight loss journey.  
*Helen Doyle (RNIB), Denise Rawden (Retina UK), Bhavini Makwana (BAME Vision)*
- 11.15 am** Break
- 11.45 am** **The role of peer-to-peer support in achieving good outcomes for clients**  
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*
- 12.45 pm** Lunch



# Programme

- 1.30 pm**      **The importance of quality-of-life research: understanding the impact of inherited sight loss**  
Exploring the outcomes of an in-depth study on the impact of retinitis pigmentosa (RP) on patients and family members.  
*Matias Segovia (Oxford Eye Hospital),  
Kate Arkell (Retina UK)*
- 2.30 pm**      Break
- 3.00 pm**      **Supporting you to deliver equitable, accessible and inclusive services**  
Practical advice on how you can offer inclusive services for people with inherited sight loss.  
*Stephen Kill, Rebecca Lunness & Joanne Kennedy (SeeAbility), Terri Balon (RNIB), Bhavini Makwana (BAME Vision)*
- 4.00 pm**      Close



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the  
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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.

# 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.

RETINA UK  
Day 2024



Thursday,  
10  
October  
2024



**#RetinaUKDay**

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

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

SIGN UP HERE:





**Matias Segovia**  
**Research Nurse, Oxford Eye Hospital**

Matias gained his Nursing Degree in 2017, graduating with honours in Malaga, Spain. He began working as a District Nurse just after the end of his last year, before relocating to the UK. There he spent two years working in the Specialist Surgery Ward at the John Radcliffe Hospital, managing the care of many different patients. Working as part of a multi-disciplinary team, patients under his care included those receiving Plastics, ENT, Maxillo-Facial and Ophthalmic treatment. During this time, Matias focused his expertise in the ophthalmic field, undergoing a Post-Graduate Certificate in Advanced Patient Centred Ophthalmology Care. This led to his current position as a Research Nurse in the Eye Research Group Oxford, at the John Radcliffe Hospital. In this role Matias coordinates multiple clinical trials, bringing with him specialist knowledge and experience, ensuring top-quality care and positive engagement for his participating patients.



**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.



## **Bhavini Makwana** **Chair of BAME Vision**

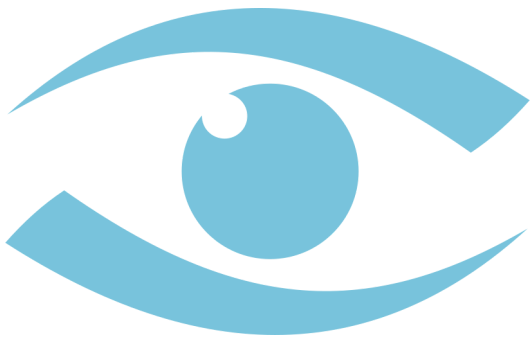
Bhavini works as a Campaigns and Projects Manager for a sight loss charity and is the Chair of BAME Vision, which formed in 2020. She is also the London and South East Group Facilitator, and an Ambassador, for Retina UK.

Bhavini was diagnosed with retinitis pigmentosa when she was 17, and received her genetic diagnosis 20 years later, giving her the answers to questions she had for so many years. She is a mother, wife and a proud owner to her beautiful and full of character Guide Dog Colin.

Bhavini aims to empower those with vision impairment by sharing resources, signposting to information, and sharing lived experience stories to break down barriers and stigma around sight loss and eye health, in particular in ethnic minority communities.

Visit [bamevision.org](https://bamevision.org) for a variety of blogs, vlogs, webinars and much more.





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## **For further information please contact:**

Eye Correction Centre

Locations across the North of England and North Wales

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Email: [referrals@eyecorrectioncentre.co.uk](mailto:referrals@eyecorrectioncentre.co.uk)

[www.eyecorrectioncentre.co.uk](http://www.eyecorrectioncentre.co.uk)



**Stephen Kill**  
**National Eye Care Services Development**  
**Manager, SeeAbility**

Stephen has worked with people who have sight loss and additional disabilities since qualifying as a Vision Rehabilitation Worker in 1995 at the University of Central England in Birmingham.

He has worked as a community-based Rehabilitation Officer with Sight for Surrey and in 2000 joined SeeAbility as a Senior Rehabilitation Practitioner where he worked with people with complex needs and sight loss in residential, day service and supported living settings.

In 2006, Stephen joined SeeAbility's team working to transform eye care and vision for people who have learning disabilities across the UK. Since then, his role has expanded from local to a national one.

Stephen's current role involves continuing to work to increase access to eye care and vision services for people with learning disabilities with a particular focus on the Easy Eye Care service.



## **Rebecca Lunness** **Eye Care Champion, SeeAbility**

Rebecca has worked for SeeAbility for five years as an Eye Care Champion in the Northwest. She has lived experience of having a learning disability and talks to groups of people with learning disabilities about how to look after their eyes. She also delivers presentations to professionals to make them “eye care aware”.

She is part of an organisation called Bury People First which is a self-advocacy organisation for people with learning disabilities who live in Bury. She is also a Trustee for Bury People First and Jigsaw, a social and sport group in Bury.

She is an accredited Oliver McGowan Tier 1 trainer.



**Joanne Kennedy**  
**Eye Care Champion, SeeAbility**

Joanne has worked for SeeAbility since 2019. Her role is to raise awareness of the importance of eye care for people with learning disabilities. She speaks from lived experience of having a learning disability. She attends events and delivers presentations to people with learning disabilities, autistic people, family carers, support providers and health professionals. Joanne also promotes Easy Eye Care, which provides specialist sight tests to people with learning disabilities in the North West.

Beyond SeeAbility, Joanne has a wealth of experience of the learning disability sector. In 2023, she was awarded the Derek Russell Award as an Outstanding Leader in the North West. She is a volunteer for Pathways Associates and is an accredited Oliver McGowan trainer. She is also part of the LeDeR Staying Alive and Well programme, working to stop people with learning disabilities and autism dying too early.



## **Terri Balon**

### **Regional Campaigns Officer (North West), RNIB**

Terri has over 20 years' experience of working in the voluntary sector, working with health and social care services, forging good collaborative working relationships with them. She is dedicated and passionate about empowering people to make informed decisions and the resourcing of staff and services to facilitate that, in roles as a trustee and volunteer with national and local disabled people, organisations and charities over the years.

She works collaboratively with public, voluntary and private sector organisations along with people with lived experience around access and accessibility, with improvements in areas such as the Glade of Light Memorial to the Manchester bomb victims, the ongoing installation of tactile maps for all in venues such as train stations and how consultations can be made accessible.

Along with colleagues she is involved in RNIB's work to support health and social care to implement the Accessible Information Standard.



## **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.

# Take part in the Retina UK Raffle for your chance to win £1,000!

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our vital work. Up for  
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part today:*





# Retina UK

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