



# RETINA UK



WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

## Retina UK Professionals' Conference

Kents Hill Park Training and  
Conference Centre, Milton Keynes

27 September 2019



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## Sponsors

Thank you to our event sponsors for their support in delivering the Retina UK Professionals’ Conference 2019.



# Welcome

Welcome

On behalf of Retina UK's trustees and staff, a very warm welcome to our first Professionals' Conference.

We are delighted you have chosen to join us in Milton Keynes today.

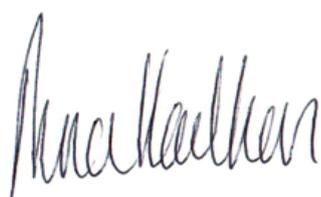
We have a packed and varied programme ahead of us. We will update you on the latest research into inherited sight loss conditions and provide information to help you to deliver the best support you can for those affected by these conditions.

We will also hear first-hand from a number of people affected by inherited sight loss, so that we can learn from their experiences.

The programme has been informed by professionals we are in touch with and feedback from our community, including the findings from our recent Retina UK Sight Loss Survey.

Thank you to all the speakers who have kindly agreed to share their wide ranging expertise and experience with us and our sponsors, exhibitors and volunteers.

The Retina UK team is on hand to help, please don't hesitate to ask if you have any questions or require assistance. Thank you for joining us and enjoy the day.



Tina Houlihan  
Chief Executive, Retina UK

# Delegates' information

In this section you will find information about the day which you may find helpful. Should you have any queries please don't hesitate to speak with a member of Retina UK staff, or the venue team.

## Wifi login details

Wifi is available throughout the conference centre. The Wifi name is Kentshill, and the password is also kentshill.

## Social media

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

## Refreshments

Refreshments are available throughout the day. Tea and coffee stations will be in place during breaks. We are providing a convenient packed sandwich lunch, which will be made available in the exhibition room.

## Sighted guides

We are delighted to have a number of volunteer sighted guides on hand to assist throughout the day. If you require assistance at any time, please make yourself known to a member of the team. We would like to thank these volunteers for their time.

## Guide dogs

Water bowls have been placed throughout the venue for guide dogs. Guide dogs can be taken to spend on the grassed area in the centre of the venue. Please ask a member of the team for directions if required.

## Feedback

We very much hope you enjoy today's event. Your feedback is important to us as it enables us to ensure we best meet our community's needs. Please do let us know about your experience today or make a suggestion for future events; a feedback form is included in your delegate pack. Simply fill in and drop off the form at the registration table on your way out, or give it to any member of the Retina UK team.

# Exhibitors

Please visit the exhibitor stands in the exhibition room. We have representatives from the following organisations:



# Conference Programme

09:00am	<b>Registration and Exhibitors</b>
10.00am	<b>Introduction and Housekeeping</b>
10:10am	<b>Welcome from the Chief Executive</b> Tina Houlihan, Retina UK Chief Executive
10:30am	<b>Update on Genetic Testing in Inherited Retinal Dystrophies</b> Professor Susan Downes, Oxford University
11.00am	<b>Update on Potential Therapies for Inherited Retinal Dystrophies</b> Samantha De Silva, Medical Retina Fellow at Moorfields Eye Hospital
11.30am	<b>Medical Q&amp;A</b> Professor Susan Downes, Samantha De Silva, Kate Arkell
12.00pm	<b>Lunch</b>
12.50pm	<b>Experts by Experience</b> People living with inherited, progressive sight loss share their stories <ul style="list-style-type: none"> <li>• Childhood Onset IRDs</li> <li>• Adult Onset IRDs</li> <li>• Dual Sensory IRDs</li> </ul>
2.20pm	<b>Tea/Coffee</b>
2.50pm	<b>The Impact of Progressive Sight Loss on Mental Health</b> Barbara Norton
3.20pm	<b>How Retina UK Can Support You</b> Retina UK Services Team
3.40pm	<b>Closing Questions</b>
3.55pm	<b>Closing Remarks</b> Tina Houlihan

# Speakers & Presenters



## Tina Houlihan

Tina Houlihan is Chief Executive at Retina UK. Since joining the charity, four years ago, 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 co-chairing the Vision UK Research Cures & Treatment Panel and 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 benefit to those the charity represents. She leads a team committed to making sure that our community is being heard, getting the very best information and services and that the charity has the greatest possible impact. A Retina UK Sight Loss Survey was undertaken in early 2019 identifying exactly what people living with, and close to, inherited sight loss want and need. Those outcomes have informed the future direction and activity of the charity.

Tina has 15 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 Graduate Law degree



### **Professor Susan Downes**

Professor Susan Downes MB ChB MD FRCOphth qualified in 1986 and is a Consultant Ophthalmic Surgeon and an Honorary Senior Lecturer at the University of Oxford. She is a member of the British Medical Association, Medical Defence Union and the Association for Research in Vision and Ophthalmology. She is also

chair of the Retina UK Medical Advisory Board.

She specialises in cataract surgery, vascular retina including diabetes, medical retinal conditions including age-related macular degeneration, laser surgery including photodynamic therapy, transpupillary thermotherapy, conventional (but not refractive) laser surgery and inherited ophthalmic eye disease.



### **Barbara Norton**

Barbara Norton is an experienced Social Worker/Counsellor having worked in Local Authority, Hospital and Voluntary Sector contexts.

She has helped to pioneer the provision of professional counselling, in a multi-disciplinary team, at the point of diagnosis of retinal dystrophies and has

spoken widely on this subject at medical and social work conferences, plus patient support groups. She was a founder

member of the UK Eye Genetics Group and a member of the patient advisory group for the Regard study.

Barbara worked as the counsellor in the specialist Retinal Dystrophy clinics at Moorfields Eye Hospital in London from January 1992 until May 2019. She was part of the multi-disciplinary team led first by Professor Alan Bird and more recently by Professor Andrew Webster. She also worked with Professor Tony Moore.

Based on her personal experience of a retinal dystrophy, Barbara has contributed widely to the work of charities for the visually impaired. She has served on both the Management and Welfare Committees of Retina UK (formerly the BRPS and RP Fighting Blindness), as well as being a founder member of our Helpline team. She is currently working with her sixth guide dog and has been a guide dog fundraising speaker for 28 years.



### **Samantha De Silva**

Samantha de Silva MA MRCP FRCOphth DPhil qualified from the University of Oxford in 2003 and completed her ophthalmology clinical training in the Oxford deanery with subspecialist training at the John Radcliffe Hospital, Oxford.

She was awarded a Wellcome Trust clinical research training fellowship to undertake a DPhil (PhD) under the supervision of Professors Robert MacLaren and Mark Hankins to investigate laboratory based gene

therapy approaches to restore visual function in end-stage retinitis pigmentosa, for which she was awarded several prizes including being named the Royal Society of Medicine/ Wesleyan trainee of the year in 2014 and the Royal College of Ophthalmologists Fight for Sight award in 2018.

She is currently a medical retina fellow at Moorfields Eye Hospital, London and honorary research associate at the University of Oxford gaining further subspecialist experience of medical retina and inherited retinal diseases.



### **Kate Arkell**

Kate began her career at the Motor Neurone Disease Association in a research communication role, developing print and digital information and responding to queries from those affected by the disease. She was also involved in research grants administration and moved on to manage research activity at

the Progressive Supranuclear Palsy Association. Kate joined the Retina UK team as Research Development Manager in January 2019 and is keen to facilitate the IRD community's engagement with research.

# RETINA UK

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