

**RETINA UK**

**WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS**

# Retina UK Annual Conference & AGM

Kents Hill Park Training and  
Conference Centre, Milton Keynes  
28 September 2019



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## Sponsors

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



# Welcome

## Welcome

On behalf of Retina UK's trustees and staff, a very warm welcome to our 43rd annual conference.

Whether you have been attending our conferences for many years, or you are joining us for the first time, we are delighted you have chosen to be here today.

We have a packed and varied programme ahead of us, focussing on the latest research into inherited retinal conditions and the information and support available.

Today is your event and the programme has been informed by the feedback we have received from our community during the past year and findings from our recent Retina UK Sight Loss Survey.

Thank you to the speakers who have kindly agreed to share their wide ranging expertise and experience with us and to our sponsors, exhibitors and volunteers who help us to make this annual event such a positive and informative experience.

Our staff and volunteers are on hand to help you so please don't hesitate to ask if you require assistance.

Thank you for joining us and enjoy the day.



Tina Houlihan  
Chief Executive, Retina UK

Information about the day ahead is available in a digital format on the conference page on our website  
**[www.RetinaUK.org.uk/annual-conference](http://www.RetinaUK.org.uk/annual-conference)**.

# 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 the 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 #RetinaUKConf. We'll also be uploading photos and updates on our Facebook page.

## Medical Question Time

To ensure our panel of experts is able to cover as many of your questions as possible in the time available, you have been issued with a couple of cards. Simply jot down your question(s) and submit your card to the Retina UK stand in the exhibition room before the end of lunch. If you would like any assistance with this, or more cards, please ask a member of Retina UK staff or one of our volunteers.

## Refreshments

Refreshments are available throughout the day. Tea and coffee stations will be in place during breaks, and biscuits will also be available. We are providing a packed sandwich lunch, which will be made available in the exhibition room. You are welcome to sit and eat in one of the workshop rooms or return to the main conference room should you wish.

## Sighted Guides

We are delighted to have a number of volunteer sighted guides who will be 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.

# Conference Programme

09:00am	<b>Exhibition stands and registration open</b>
10.15am	<b>Conference Welcome</b> Don Grocott, Retina UK Chairman
10:20am	<b>Chief Executive's Address</b> Tina Houlihan, Retina UK Chief Executive
10:30am	<b>The London Project to Cure Blindness at 10 years, have we found a cure?</b> Professor Pete Coffey, University College London
10.55am	<b>Optogenetics for inherited retinal degenerations: an introduction</b> Michael Gilhooley, University of Oxford
11.20am	<b>Tea and Coffee Break</b> With a chance to view the stands and chat
11.45am	<b>Inspirational Speaker</b> Lizzie Capener
12.10pm	<b>Working Together – the importance of international collaboration</b> Avril Daly, Retina International
12.35pm	<b>Lunch</b> Lunch is provided in the Exhibition Room
1.35pm	<b>Research and Retina UK – process and successes</b> Professor Susan Downes, Chair of Retina UK's Medical Advisory Board

2.00pm	<p><b>Workshop option one:</b> OXSIGHT – Transforming Lives Through Technology Main Room</p> <p><b>Workshop option two:</b> Barbara Norton – Adjusting to life-changes caused by progressive sight loss Room Two</p> <p><b>Workshop option three:</b> Davinder Kullar, RNIB – Solutions Through Technology Room Three</p>
2.45pm	<p><b>Tea and Coffee Break</b> With a final chance to view the stands and chat</p>
3.10pm	<p><b>The John Marshall Award – RP Scientist of the Year presentation</b></p>
3.15pm	<p><b>Ask the Experts: Medical Question Time</b> Chaired by Professor John Marshall MBE who will be joined by medical speakers</p>
4.15pm	<p><b>Conference Close</b> Don Grocott, Retina UK Chairman</p>

4.30pm	<p><b>Annual General Meeting</b> The formal business matters of the charity Members are encouraged to attend.</p>
5.00pm	<p>Event Close</p>

# Workshops

You have already chosen your workshop option. If you have forgotten which workshop you are booked on to, you can find it written on your delegate name badge.

Should you have any queries about workshops a member of the Retina UK team will be happy to help.

## Workshop locations

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### Main Room – **OXSIGHT**

Transforming Lives Through Technology

We understand everyone's eye condition is different but if our glasses suit your eyes then the experience will be... well, an eye opener. Come along to understand the technology behind innovative OXSIGHT glasses.

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### Room two – **Barbara Norton**

Adjusting to life-changes caused by progressive sight loss

A loss of confidence, anxiety and stress are normal emotions experienced by almost all families affected by inherited progressive sight loss at some time. Sight loss counsellor Barbara Norton will discuss common triggers, share practical tips on how to cope, and suggest where to turn for support.

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Room Three - **Davinder Kullar, RNIB**  
Solutions Through Technology

No vision or a reduction in vision presents a range of challenges to an individual's life. These can be blockages and barriers until effective solutions can be put in place. For instance, difficulty reading and accessing print material, communicating in an increasingly digital world, having access to knowledge and research on the world's biggest library called the internet.

This workshop is aimed at providing people with an insight into how technology can be utilised effectively to overcome barriers faced in light of no sight or low sight.

A range of solutions to the challenges described above will be discussed, including how the technology can be adapted, and the applications and features used to add quality to a blind or partially sighted person's life.

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# AGM Agenda

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1. Chairman's welcome

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  2. Introductions

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  3. Apologies

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  4. Approval of the minutes of the previous AGM

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  5. Annual Report and Accounts for 2018
    - (a) Introduction
    - (b) Questions from the floor
    - (c) Resolution: to adopt the Report and Accounts for 2018

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  6. Resolution: To appoint Baldwins Audit Services as auditors

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  7. Resolution: The Retirement and Re-election of trustees.
    - (a) The following trustees retire by rotation and are standing for re-election:  
Lucy Withington  
Roger Backhouse
    - (b) The following trustees retire by rotation and are not standing for re-election:  
Colin McArthur

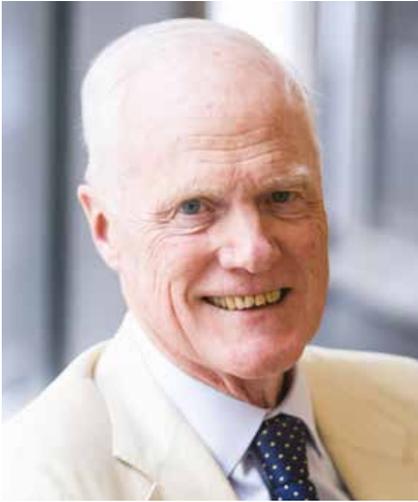
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  8. Any other business

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  9. Chairman's closing remarks

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### **Don Grocott**

Don Grocott TD MA FRSA FIoD is Chairman of the Board of Trustees at Retina UK. He was appointed to the board in early 2009 and became Chairman of the charity in June 2011. Don is a Past Master of the Worshipful Company of Spectacle Makers, and is well known across the optical world. He was President of the Association

of Optometrists and President of the Federation of Ophthalmic and Dispensing Opticians, before spearheading the formation of the Optical Confederation to bring together key players in optics to present a co-ordinated view to government on issues affecting UK optical professionals, manufacturers, retailers, distributors and importers. Don has been Chairman of the Association of Contact Lens Manufacturers and President of Euromcontact, the European contact lens manufacturers' federation. He is currently the director of a small cancer charity and holds board appointments in two private healthcare initiatives.



### **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.

## Speakers & Presenters

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 benefits 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 Pete Coffey**

Professor Pete Coffey, DPhil, is Theme Lead of Development, Ageing and Disease at UCL's Institute of Ophthalmology and the Co-Executive Director of Translation at UC Santa Barbara's Center for Stem Cell Biology and Engineering. He is the principal author and co-author of two landmark papers demonstrating the

use of human cells to halt visual deterioration in models of age-related macular degeneration. His achievements include the launch of the London Project to Cure Blindness, which aims to develop a stem cell therapy for the majority of all types of age-related macular degeneration, seminal work on retinal transplantation (as described by Debrossy & Dunnett, Nature Neuroscience 2001). Professor Coffey has received many honors and awards, including the prestigious Estelle Doheny Living Tribute Award in 2009, Retinitis Pigmentosa International's Vision Award in 2009, the CIRM Leadership Award in 2010, and the New York Stem Cell Foundation Roberston Prize in 2011. Finally, in 2018, the results of two patients were presented in which an engineered biopolymer with stem cell derived retinal pigment epithelium cells were implanted into the eye. Not only did this demonstrate that regenerative medicine is feasible but resulted in the sustained recovery of reading in blind patients with sudden severe vision loss from Macular Degeneration – a breakthrough validating the stem cell treatment paradigm.



### **Michael Gilhooley**

Originally from Ayrshire, Michael is an ophthalmology specialist trainee in London. For the last three years, he has been funded by the Wellcome Trust to carry out research at the Nuffield Laboratory of Ophthalmology in Oxford. Working under the supervision of Professors Downes and Hankins, his research interest is

in optogenetics. This promising technique aims to stimulate retinal cells (such as nerve cells) that survive during inherited degenerations in order to return a degree of vision.



### **Lizzie Capener**

TV's First Blind Soprano Judge! Lizzie is a soaring Soprano, having sung at some of the most prestigious music venues in the world.

Alongside her cricket career (she plays for Surrey Visually Impaired Cricket Club), she has sung with the Orchestra of the Age of Enlightenment and The King's Consort, as well as making several recordings and broadcasts for BBC Radio 3, World Service, and Classic FM. She has appeared at the Three Choirs', Southern Cathedrals' and Windsor festivals, in numerous cathedrals, abbeys and major venues throughout the UK, and in France, Belgium, Germany, Greece and the USA, including being invited to sing Handel's setting of the Gloria for solo Soprano in Falmouth in Cape Cod.

She successfully completed a PGCE in Secondary Music at Greenwich University and Trinity College of Music in 2007.



### **Avril Daly**

Avril Daly is the CEO of Retina International, the global patient-led umbrella group dedicated to the promotion of research into Rare and Inherited, as well as Age-related, forms of retinal degenerative conditions. She previously held the position of CEO at Fighting Blindness Ireland for eight years.

Avril is the Vice President of EURORDIS (Rare Disease Europe) and chair of the Irish National Alliance for Rare Diseases (RDI). She has been chairperson of the Genetic and Rare Disorders Organisation (Rare Disease Ireland) since 2009.

She was a member of the Medical Research Charities Group (MRCG), the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI). She served two terms as Board Member of the European Patients Forum (EPF) and as Board member of European Platform for Patients Organisations Science and industry (EPPOSI) for two terms.

She was diagnosed with retinitis pigmentosa in 1998. She has been a patient advocate for many years with a particular focus on working towards improved funding and infrastructures for research into rare conditions, clinical trial development for small populations and access to medicines for unmet need.



### **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.



### **Professor John Marshall MBE**

Prof John Marshall MBE is the Frost Professor of Ophthalmology at the Institute of Ophthalmology at University College London; 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. He is one of Retina UK's longest serving trustees.

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.

# Exhibitors

Please take time to visit the various exhibitor stands that are situated in the exhibition room. We have representatives from the following organisations:



**BRITISH WIRELESS  
FOR THE BLIND FUND**

KEEPING BLIND PEOPLE IN  
TOUCH WITH THE WORLD



**R N I B**

**See differently**



# RETINA UK

**WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS**

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