

RETINAuk

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

Retina UK Annual Conference & AGM

17 April 2021



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How to access the conference

The conference is being held virtually and cameras will not be switched on. To access the conference, please follow the link on our website:

www.RetinaUK.org.uk/annual-conference.

In the unlikely event the link is not working on the day, or you have trouble accessing it, you can use this alternative link:

www.fundraisingeverywhere.com/retinaukconf.

Welcome

Welcome

On behalf of Retina UK's trustees and staff, a very warm welcome to what is our 44th annual conference, but our first online.

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

We have a busy programme focussing on the latest research into inherited retinal conditions and the information and support available. Our morning sessions focus on the importance of genetic testing and counselling as today marks the launch of our important new resource Unlock Genetics – www.RetinaUK.org.uk/genetics

There will be plenty of opportunities throughout the day to ask questions and I would encourage you to do so by using the online chat, by email or phone.

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

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.

Questions

As you will not be able to raise your hand to ask questions on the day, we have a number of ways for you to find out about what is important to you. You can:

- Submit your questions in advance
Please send your question via email to **info@RetinaUK.org.uk**, remember to include your name and the session that it relates to. If you are not able to email us, you can contact our team on 01280 821334.
- Email us on the day
You can email any questions on the day to **info@RetinaUK.org.uk**.
- Telephone us on the day
Our friendly team will be available to take your questions over the phone during the conference. Simply call us on 01280 821334.
- Submit your question on the conference website
There is an interactive chat feature that you can use to submit questions, simply type in your question and click send.

Please be aware that we may not be able to ask our speakers all of the questions we receive, but we will endeavour to get answers for as many as we can.

Technical support

If you are unsure of how to access the conference, please contact the team ahead of the day and they will arrange support for you, you can either email services@RetinaUK.org.uk or telephone 01280 821334.

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

Feedback

Your views are important to us, please take a few minutes to share your feedback after the event by completing the form here: <https://www.surveymonkey.co.uk/r/YJ6Y8TD>.

AGM Agenda

The formal business matters of the charity will be discussed at the **Annual General Meeting**. Members are encouraged to attend. It will start at 9.30am.

1. Chairman's welcome

2. Introductions

3. Apologies

4. Approval of the minutes of the previous AGM (result of online voting)

5. Presentation of the annual report and accounts for the year ended 31 January 2019 and 2020 overview

6. Adoption of the Annual Report and Accounts for 2019 (result of online voting)

7. The appointment of the auditors (result of online voting)

8. Presentation of Retina UK activity in 2019 and 2020 overview – Chairman Don Grocott

9. The appointment of trustees (result of online voting)

10. Any other business

11. Chairman's closing remarks

Conference Programme

These timings are for guidance only and may change

9.30am	Retina UK AGM Non-members are welcome to attend but are unable to speak or vote on any resolution
10.00am	Chairman's welcome and address Don Grocott, Chairman, Retina UK
10.05am	Chief Executive's welcome and address Tina Houlihan, Chief Executive, Retina UK
10.15am	Genetics – how does it affect you? Georgina Hall
10:45am	Genetics research Professor Alison Hardcastle
11:10am	Unlock Genetics Denise Rawden and Kate Arkell
11.25am	Genetics Q&A
12.00pm	Break
12.15pm	Update from industry (inc. Q&A) <ul style="list-style-type: none"> • Jens Schaumann, Okuvision • Jennifer Pluim, ProQR
12.45pm	Research update (inc. Q&A) Samantha De Silva
2.00pm	Annual Conference summary and close Don Grocott

Speakers & Presenters

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.

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.

Samantha De Silva



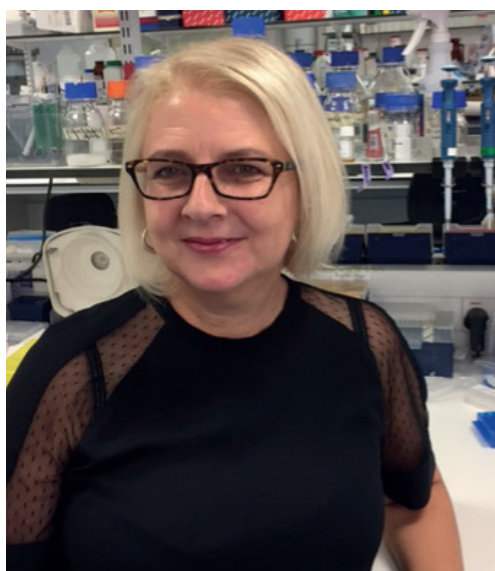
Samantha de Silva MA(Cantab) MRCP FRCOphth DPhil is a Consultant Ophthalmologist specialising in medical retina disorders at the Oxford University Hospitals NHS Foundation Trust, honorary research fellow at the UCL Institute of Ophthalmology and at the University of Oxford.

After graduating from the Universities of Cambridge and Oxford, she completed ophthalmology training in the Oxford

deanery. She was awarded a Wellcome Trust fellowship to undertake doctoral research into optogenetic gene therapy, to investigate strategies to restore vision in end-stage inherited retinal degenerations, leading to high impact publications. This was followed by two fellowships in medical retina, sub-specialising in inherited retinal disease, in Oxford and at Moorfields Eye Hospital, London.

Samantha has given numerous invited lectures, and sits on the Women in Vision UK committee, promoting the role of women in ophthalmology and visual sciences. She has received over 20 awards including the Royal College of Ophthalmologists Harcourt medal (2008), been named the Royal Society of Medicine/Weslyan trainee of the year (2014) and won the RCOphth/Fight for Sight prize (2018).

Professor Alison Hardcastle



Professor Alison Hardcastle has been involved in vision research since her undergraduate studies at the old Institute of Ophthalmology near Kings Cross. Award of a Fight for Sight PhD studentship enabled Alison to study molecular genetics at the University of Newcastle upon Tyne, supervised by Prof. Shomi Bhattacharya. In 1992,

they moved to the new Institute of Ophthalmology, next to Moorfields Eye Hospital, and established the Department of Genetics.

Alison continued her postdoctoral and academic career at UCL Institute of Ophthalmology, initially with a focus on X-linked

Speakers & Presenters

retinal dystrophies, identifying new genes and defining their function in the eye. She was appointed Lecturer in 2000 and promoted to Professor of Molecular Genetics in 2009. In 2015, Alison was appointed Deputy Director at UCL Institute of Ophthalmology. In this role, she is developing research strategy and supporting early career researchers to reach their potential and remain in vision research. In 2016, she was awarded the Jessie Mole medal for her contribution to research on retinal dystrophies. Alison was conferred a personal Chair in 2019, and is now Sembal Professor of Experimental Ophthalmology.

Research in her lab harnesses technological advances in next generation sequencing and stem cell biology, and has identified many new genes and genetic mechanisms that cause retinal diseases such as RP and cone dystrophies. Differentiation of pluripotent stem cells to retinal pigment epithelium and 3-dimensional retinal organoids enables her team to study disease mechanisms and test potential therapies.

Georgina Hall



Georgina Hall is a GCRB Registered Consultant Genetic Counsellor and Honorary Lecturer. She has worked in the Manchester Centre for Genomic Medicine since 1995.

Her specialist interests include ophthalmic genetics, co-ordinating a number of research grants including a Fight for Sight programme grant (2010–2015) to develop services for inherited retinal dystrophy and quality

improvement work such as improving access to genetic testing for children with cataracts (2017). She leads the Genetic Eye team in Manchester, delivering multidisciplinary clinics with paediatric ophthalmology and adult retina in Manchester Royal Eye Hospital. Ms Hall has worked closely in the development of molecular MDTs for interpretation of genomic results and is involved with the clinical team delivering gene therapy treatment for RPE 65 at Manchester Royal Eye Hospital. Ms Hall was Chair of the Association of Genetic Nurses and Counsellors (2005). She led the successful application for statutory regulation by the HPC (2009) and chaired the Joint Committee on Genetic Counsellor Regulation. Ms Hall has an active role in genetic counselling education, running modules on the STP in Genomic Counselling, the MSc Genomic Medicine and is clinical lead on a joint PGCert with PUHSC in Beijing.

Kate Arkell



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.

Denise Rawden

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. The volunteers provided emotional support and practical information to help them navigate the difficult journeys ahead.

Denise joined Retina UK in 2013, managing and supporting the 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 organising events, attending sight loss exhibitions and supporting the Helpline and Talk and Support services.

Jennifer Pluim, ProQR

Jennifer is Vice President Medical Affairs and has over



25 years' experience in the pharmaceutical industry, with extensive knowledge in clinical operations, project management and medical affairs. Her experience spans several therapeutic areas, where she has been involved in developing the medical affairs strategy of therapeutic targets in infectious diseases, respiratory critical care, cardiovascular disease, oncology and ophthalmology.

For the past 8 years, she had a

leadership role at Bayer in developing the medical strategy for Eylea®- an anti-VEGF for the treatment of retinal diseases. During her career, she has had the opportunity to work for both big pharma as well as start-up biotechnology companies, where she has built and led a medical affairs organization and infrastructure. Jennifer earned a B.S. in Microbiology and an MBA from The Pennsylvania State University, certification as a Medical Technologist (M.T.) and Project Management Professional (PMP) and has received additional training in pharmacoepidemiology and real-world evidence.

Jens Schaumann, Okuvision

Jens is responsible for all things communication at Okuvision



GmbH. In his role he nurtures close relationships with patients, patient groups, clinicians, healthcare payers and the public. Before joining Okuvision, he was responsible for Market Access and the UK operations of Retina Implant. He has been navigating the medical device space since 2011, when he began collaborating with start-ups in London and Canada on new cancer screening and glucose monitoring modalities.

His first professional background is in architecture, which he uses until today to build lasting and sustainable relationships instead of buildings.

Sponsors

Thank you to our event sponsors for their support in delivering the Retina UK Annual Conference 2021.

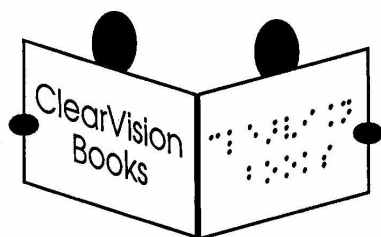


Exhibitors

Representatives from the following organisations are involved in the Conference today:



www.sightandsound.co.uk
01604 798070
info@sightandsound.co.uk



UN|LOCK|K Genetics

Discover Your Choices

Genetic testing may help you and your family discover more about your inherited sight loss condition and how to unlock choices.



**Prefer print or
audio format?**

Call **01280 821334**
or Email **info@RetinaUK.org.uk**

RETINAuk

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

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