

LOOK FORWARD



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Welcome to your Spring 2019 edition of Look Forward which includes information about our Annual Conference in September, our survey and exciting updates from fundraising and research activity.

This is your publication and we'd love some feedback on what you would like to see in future editions. Please call Jane on 01280 821334 or email communications@RetinaUK.org.uk with your suggestions. We'd also like to encourage you to follow Retina UK on social media.

Springing into action



It's always a joy when spring arrives and longed-for lighter evenings.

For some this time of year brings renewed energy and I know many of you, including Retina UK staff, are channelling this to raise funds for our charity by taking part in sponsored runs, cycles, treks and all manner of physical challenges.

Thank you and good luck to you all, including

our 26-strong London Marathon team – we will all be cheering you on!

The Big Give Christmas Challenge and Christmas raffle seem a long time ago, but I want to thank each and every one of you who showed your support. Together you raised more than £46,500 to help fund our vital research including Prof Frans Cremers' study which is revealing hidden genetic clues that could lead to treatments for Stargardt disease and developing techniques for studying other retinal conditions.

Retina UK is your charity and we need to remain confident we are responding to your needs. To help us better understand

these, please complete our inherited sight loss survey (see page 3). Thanks to everyone who contributed to our working age research, we will use the findings to provide better support in this area.

Do send me an email at chiefexec@RetinaUK.org.uk if you have any thoughts to share about our charity. Or speak with any of the team at our many events, including our annual conference, which you can read about in this newsletter. Thank you for your ongoing support.

A handwritten signature in blue ink that reads "Tina Houlihan".

Tina Houlihan, Chief Executive

Retina UK funds medical research into inherited sight loss and offers a range of information and support services to those affected.

Retina UK, Wharf House, Stratford Road, Buckingham MK18 1TD

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Do you follow us on Facebook and Twitter? Search for Retina UK on Facebook to find our page and various groups, and follow us on Twitter at [@RetinaUK](https://twitter.com/RetinaUK) for the latest news and updates about the charity.

Your views matter

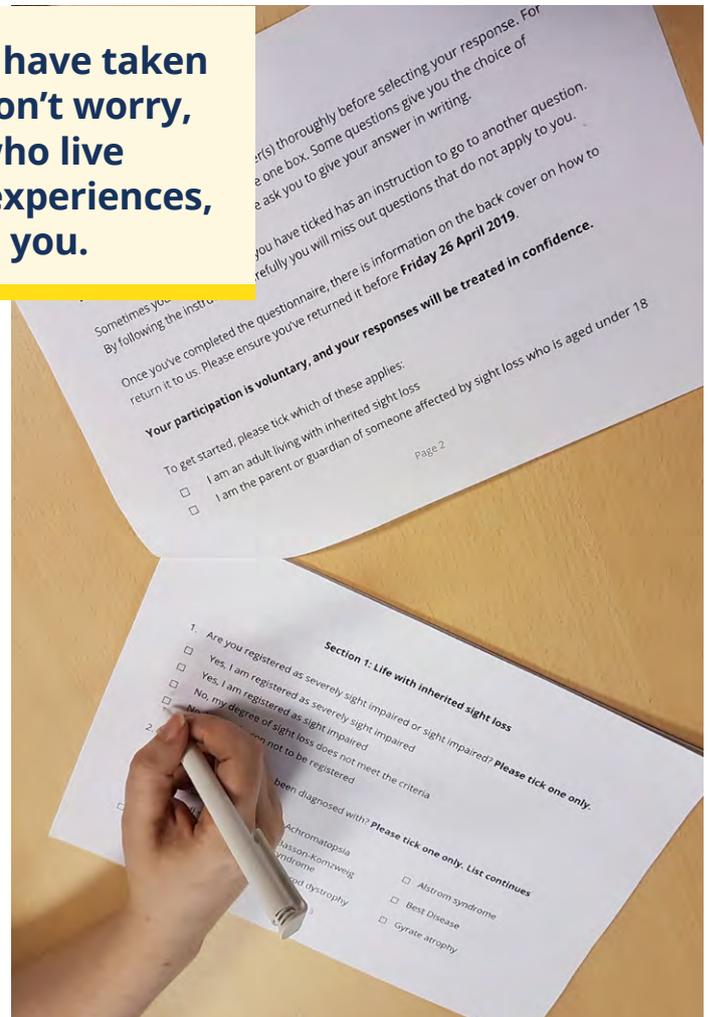
Are you one of the 700 plus people who have taken part in our community survey? If not, don't worry, there's still time. We are asking those who live with inherited sight loss to share your experiences, views and tell us what really matters to you.

Your feedback will help us to understand how you are accessing and using information and support services, including those offered by Retina UK, and how we can further improve these. You will also guide us on the role that you would like your charity to play in supporting and representing you in the future.

Retina UK Chief Executive, Tina Houlihan, said: "We are delighted with the response we have had to date and I would like to thank all those in our community who have taken the time to share their experiences with us.

"We will use the valuable information we receive to guide us so that we can be confident we are responding to your needs and that we invest our limited resources wisely to have the most positive impact for our community.

"If you have yet to complete the survey, please do take the time to do so and help shape our future as we strive to achieve our vision of a world where everyone with an inherited sight loss condition is able to live a fulfilling life."



The questionnaire can be completed on paper (large print), online, or over the phone. The closing date is 26 April.

To discuss and receive the format that best suits you, please email info@RetinaUK.org.uk or phone us on 01280 821334.



Scan this code to complete the survey

Eminent researchers confi

Eminent researchers will be among those who present at our 2019 Retina UK Annual Conference.

Places are booking fast for this popular one-day event which promises to be both informative and enjoyable. It will be held on Saturday 28 September and attendance is free of charge for Retina UK members and their guides.

All those living with or affected by inherited retinal conditions are welcome, so please bring your family and friends. If you haven't been to a Retina UK annual conference before, make this the year you join us!



We are thrilled to confirm that our Inspirational Speaker in 2019 will be Amar Latif (BBC Travelling Blind)

Speakers already confirmed include:

Prof Susan Downes (consultant ophthalmic surgeon Oxford Eye Hospital and an honorary senior lecturer at the University of Oxford)

Prof Pete Coffey (Institute of Ophthalmology, University College London)

Michael Gilhooley (clinical research training fellow at the Nuffield Laboratory of Ophthalmology and honorary registrar to Moorfields Eye Hospital)

Avril Daly (CEO, Retina International)

The venue is Kents Hill Training and Conference Centre in Milton Keynes (MK7 6BZ), a more central location, to enable more of our community to attend.

The day will include presentations and workshops on the latest research, services and support available to assist with day to day living, and our popular medical question time hosted by a panel of eminent researchers.



armed for conference



*"First time attending this event. Well worth the visit from Scotland. Great networking. Event was good, speakers awesome and all Retina UK staff are excellent. We are in safe hands."
Comment from 2018 attendee*

There will be plenty of time to get to know others in our community, to meet our friendly, knowledgeable staff and to find out more about our charity.

A packed lunch will be provided along with refreshments throughout the day. A number of exhibitors from other charities, organisations and businesses will be attending, including our generous sponsors Ox sight.

Members are encouraged to attend Retina UK's statutory Annual General Meeting which will take place at the end of the day.

Book your place

Attendance is free of charge for Retina UK members and their guides. We request a voluntary donation from other delegates to help cover costs (£30 suggested).

Registration is open now and you can book your place:

- Online: www.RetinaUK.org.uk/annual-conference
- By phone: 01280 821334
- Email: info@RetinaUK.org.uk

If you have any questions, or would like to speak to us about this event, please call us on 01280 821334.

The venue

Kents Hill Park Training and Conference Centre is located five miles from Milton Keynes Train Station. It is fully accessible and our friendly staff and volunteer sighted guides will be available to support. Plenty of free parking is available on site.

Accommodation is available at Kents Hill and this should be booked directly with the venue (www.kentshillpark.com/accommodation) by calling 01908 358000, just quote 'Retina UK'.

Gene therapy wins European approval

The gene therapy Luxturna has won European regulatory approval for the treatment of severe inherited retinal dystrophy caused by mutations in the *RPE65* gene.

Luxturna is the first and only gene therapy approved in Europe to treat inherited retinal disease and will be marketed here by the pharmaceutical company Novartis.

This milestone decision was made by the European Medicines Agency (EMA) on Thursday 22 November 2018.

There will now be significant discussions at national level to determine pricing and access to the treatment before it is made available to patients. The timeline for this is difficult to predict.

How does it work?

Luxturna works by delivering healthy, functional copies of the *RPE65* gene, via a single retinal injection, to restore levels of the enzyme and allow the visual cycle to progress normally. As demonstrated in clinical trials, this can prevent further vision loss and can restore some functional vision; patients treated with Luxturna showed significantly improved night vision one year after treatment.

The EMA has approved Luxturna for patients who have two mutated copies



of *RPE65* and still have sufficient viable retinal cells, as determined by an ophthalmologist, to benefit from the therapy. Genetic testing is essential to establish whether a person's sight loss is caused by this particular genetic fault. Luxturna will have no effect if the disease-causing mutation is in a different gene.

"Time is of the essence"

"This is a milestone decision and one that provides huge hope for those who live with inherited retinal conditions," said Tina Houlihan, Chief Executive of Retina UK. "We will now work with Novartis, the National Institute for Health and Care Excellence (NICE) and the NHS to ensure those who are able to benefit from this treatment have access to it as quickly as possible."

A more detailed article about Luxturna can be found on the Retina UK website: www.RetinaUK.org.uk/news.

Join us at our information days

We are excited to announce the dates for our 2019 information and family days.



These informal, popular events are free to attend and will include presentations from leading medical professionals and our partners within the sight loss sector. There will be the opportunity to meet with other local sight loss organisations and learn more about the work of Retina UK.

Our information days are open to:

- Anyone affected by an inherited retinal dystrophy
- Family and friends
- Professionals working with affected families
- Anyone interested in learning about this important group of eye conditions.

Newcastle Information Day

Thursday 16 May, 10.00am to 4.00pm, Bamburgh House, Market Street (East), Newcastle upon Tyne, NE1 6BH.

Brighton Information Day

Tuesday 18 June, 10.00am to 4.00pm, The Brighthelm Centre, North Road, Brighton, BN1 1YD.

Ushers syndrome family event

Saturday 22 June, Sense Touchbase Pears Centre, Birmingham, B29 6NA. We are joining with Usher Kids UK for this event to address the specific needs of families affected by Usher syndrome. Young family members can spend time with others with similar experiences, while parents and carers hear from Usher syndrome experts from the fields of ophthalmology, research, technology, education and emotional support.

Belfast Information Day

Thursday 24 October, 10.00am to 4.00pm, Grosvenor Hall at BCM, Grosvenor House, 5 Glengall Street, Belfast, BT12 5AD.

Nottingham Information Day

We are still planning our Nottingham day, we anticipate this will be held in October. We will circulate more information about this very shortly.

Please register in advance for these events

- Online: www.RetinaUK.org.uk/info-events
 - By email: info@RetinaUK.org.uk
 - By phone: 01280 821334
- We do hope to see you there.

Our Peer Support Group network

Our Retina UK Peer Support Groups meet regularly to provide information and support. They are an opportunity for individuals and families affected by inherited sight loss to engage with Retina UK, and get to know each other, in their local area.

Providing face-to-face access to information and support is the primary aim of our groups, however some also arrange social gatherings and fundraising activities.

We have groups in the East of Scotland, Glasgow, Oxford, London, South Wales, Liverpool, Somerset and the Isle of Wight.

Find out more at www.RetinaUK.org.uk/groups or call us on 01280 821334.

"It was so great to meet others who knew exactly what my own struggles and issues are, and who could offer some really helpful tips. As well as having a good laugh!

"The medical speaker was amazing. This was the first time I had got to meet other people with retinitis pigmentosa. I wish I hadn't waited so long."

London Local Group attendee

NEW FOR 2019

Liverpool

This new group meets on the last Monday of the month starting on 29 April, 1.15pm - 3.15pm at Christopher Grange Sight Loss Learning Hub L14 2EW.

Interested?
Email liverpool@RetinaUK.org.uk
or call 01280 821334.

Somerset

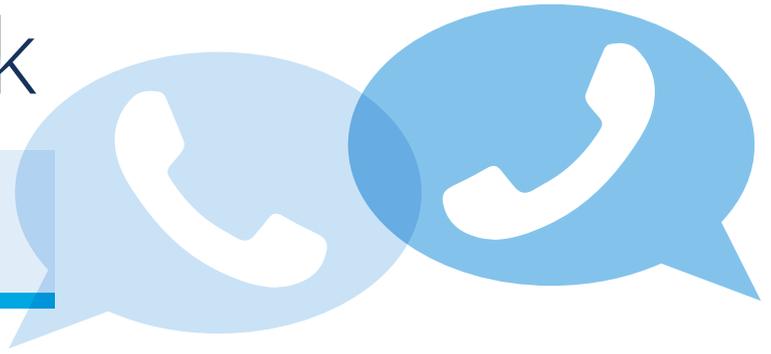
We are working with Somerset Sight to grow our Retina UK Local Somerset group. We hope to have our first meeting in June.

Interested?
Email somerset@RetinaUK.org.uk
or call 01280 821334.

Volunteer with us. To volunteer at a group in your area contact Clair at clair.pudaruth@RetinaUK.org.uk or 01280 821334

It's good to talk

It's good to talk and we all sometimes need a listening ear.



Our Retina UK Talk & Support service (previously known as our Befriending service) offers friendly phone calls from volunteers who are willing to share their experiences and give support at a time when most needed.

This service offers a social link on a more personal and longer term basis than our Retina UK Telephone Helpline, with regular calls being made by the volunteers over a period of time dependent on need.

All volunteers have personal experience of inherited retinal dystrophies.

Talk & Support is particularly suitable for those who may have difficulty attending Retina UK Local Peer Support Group meetings or our Information Days.

For more information on how to access the service, or to find out how you can become a Talk & Support volunteer, email talksupport@RetinaUK.org.uk or call 01280 821334.

Do you have experience of Charles Bonnet syndrome?

Have you had experience of Charles Bonnet syndrome (CBS)? Would you be interested in supporting others who are experiencing visual hallucinations?

We work with the charity Esme's Umbrella – www.charlesbonnetsyndrome.uk – and the RNIB Eye Health Team to suggest coping methods and provide support to individuals who live with CBS.

To find out more about this service, including how you can get involved, please contact Clair Pudaruth, Volunteer Coordinator, on clair.pudaruth@RetinaUK.org.uk or 01280 821334.

*“Just knowing that there is someone who understands and cares makes a great deal of difference. I feel we all need kind and caring people in our lives. When I am going through a low time I find the service is there to help.”
Mohammed*

On a bicycle made for

Join Paralympic gold medal winning tandem cyclist Steve Bate MBE on our brand new event, the Tandem Cycle Challenge!

From 11 - 13 October 2019, you could join #TeamRetinaUK on a challenge like no other. You will be cycling for 100 miles over two days along Hadrian's Cycleway on a tandem bicycle, and raising vital funds for Retina UK.

Steve, a Retina UK ambassador, said "I'm really excited to be supporting this event. It's a fantastic opportunity to raise money for Retina UK."

On 11 October you will arrive in Tynemouth, meet your fellow team



members and check into the first night's accommodation.

The following morning, you and your bike will be transported to the start line in Bowness-on-Solway. There will be a brief on what to expect during the day and you will set off.

There's 44 miles to cycle on day one, following miles of beautiful coastline, and passing castles, forts, turrets and abbeys. That evening you will stay the night in the lovely town of Haltwhistle, and you will have the chance to participate in a Q&A with Steve.

On the final day you will cycle 56 miles



two...



*"I want to raise as much as possible for investment into pioneering medical research that could lead to treatments for inherited sight loss as well as to fund vital services for people living with these conditions and their families."
Deborah Laing*

following the river Tyne right to the end of Hadrian's Wall at the fort of Segedunum, then on to the North Sea where you'll reach your destination at Tynemouth Priory. We will be there to congratulate you and hand out your very well deserved medals!

If you don't have a cycling partner, don't worry! You can either cycle solo on a regular bike, or we can partner you up with someone.

For the full itinerary, a list of FAQs, and to register for the challenge visit www.RetinaUK.org.uk/tandemcycle.

Register your interest by 1 May 2019.

Included in the challenge is:

- Two days fantastic cycling
- Two nights' comfortable bed and breakfast accommodation
- Transport from Tynemouth to Bowness-on-Solway at the start of the event
- All baggage transfers during the event
- Map of the route and GPS files if required
- Detailed route information including places to eat
- Vehicle backup
- The chance to attend a Q&A session with Steve Bate
- Retina UK personalised cycling jersey
- Retina UK Tandem Cycle Challenge medal when you've completed the challenge

Registration fee: £75 per person

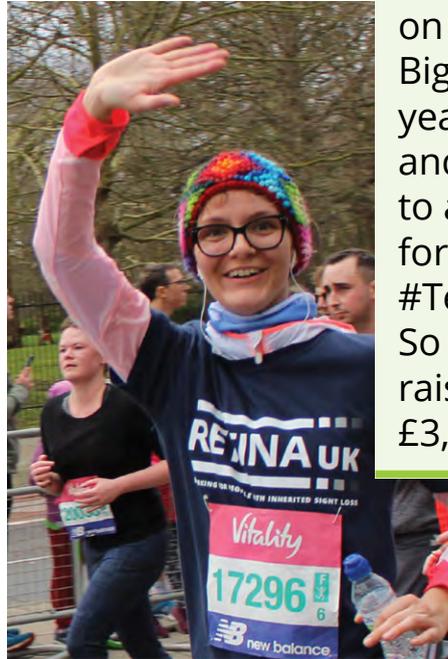
Minimum fundraising target: £325 per person

*"I don't regularly cycle and I've never been on a tandem so it will be a huge personal challenge."
Deborah Laing*

Thanks to you



Thank you to Will Ashton, Rosie Evans and Morgan Smith-Allen who took on the Exeter Half Marathon in February. Their efforts raised £1,062.

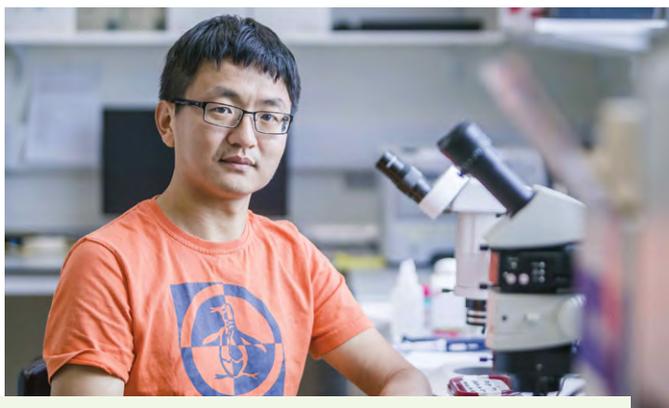


We had a team of runners taking on the Vitality Big Half this year. Well done and thank you to all of them for being part of #TeamRetinaUK. So far they have raised over £3,500!

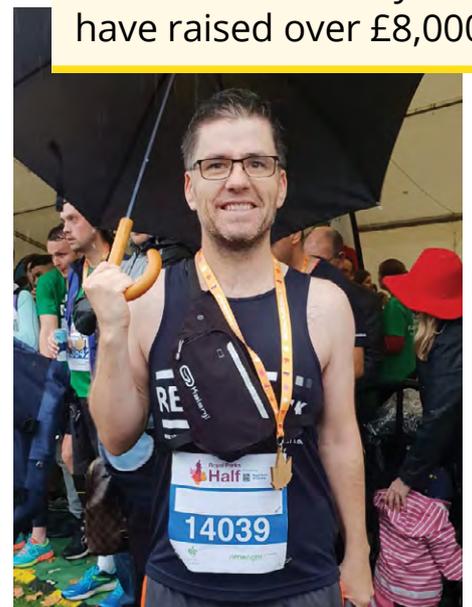
Rita Pakalniskyte

Jackie and Sarah Marshall took on personal challenges, with Jackie committing to a dry January, and Sarah shaving her head for Retina UK. Together they have raised over £500.

Thank you to our #TeamRetinaUK runners who took part in the Great North Run and Royal Parks Half Marathon last year. Between them they have raised over £8,000!



Thank you so much to the pledgers and donors who contributed to 2018's Big Give Christmas Challenge, as well as our Champions the Hospital Saturday Fund. Together you raised £31,552 for pioneering medical research.



James Birtley

We love to hear about all of the great fundraising that goes on up and down the



Saddleworth Running Club raised £580 through various events over the past year, including a cake race! Thank you to all involved!



A huge thank you to Jean Wilkinson and everyone at Lawson Fuses for supporting us every year through their Christmas raffle. This year they raised £225!



Alex Eaton and Adam Orriss took on the Cambridge Half Marathon in March and have raised £740 between them!



Thank you to Trudy Stribling who took on the Thorpe Park Half Marathon in February, achieving a personal best!



Workshop's Got Talent returned at the end of 2018, and featured celebrity guests including Kim Marsh. It was another sell-out event with 700 people attending, and raised a magnificent £8,500! Thank you so much to James Clark for his continued support.

Patrick Marshall boosted our funds by over £200 by putting on a coffee morning.

Life on the edge of new

Retina UK is currently providing funding to Prof Frans Cremers at Radboud University in The Netherlands for investigation of the significant number of Stargardt disease (STGD1) cases where there is no obvious error in the most common disease-associated gene, ABCA4.



The project aims to develop a cost effective method of examining the entire *ABCA4* gene to look for variations that might cause disease. In particular, the researchers will investigate variants hidden in the sections of the gene that do not actually code the building block 'ingredients' of the *ABCA4* protein, but nonetheless can have a significant impact on protein construction.

Our funding has enabled Prof Cremers to employ two final year PhD students, Stéphanie Cornelis and Mubeen Khan, to work on the project. Both have already made significant contributions and have been inspired to continue their careers in retinal disease research when their PhDs are finished. Stéphanie and Mubeen talked to us about how they came to study this field and about life in the lab.

Stéphanie's undergraduate and Masters degrees spanned neurology and genetics. She came to Prof Cremers' lab as a research assistant and decided to stay to undertake a PhD. "He is very knowledgeable, motivated and enthusiastic, which is contagious. He is very good at seeing the potential in people and helping that potential flourish; it's a very nice group to work in."

This supportive environment was of particular help to Mubeen, who came to work on the project from her home in Islamabad, Pakistan. "I am really close to my family, so coming here and living independently was a big step" she told us. "Cycling into work every day was particularly strange to start with! But all of my colleagues have helped me to get settled."

discoveries

Motivated to make a difference

Both students are motivated by the impact inherited retinal disease makes on people's lives. "During my Masters studies I had the chance to meet many people affected by different genetic disorders" said Mubeen. "I realised how difficult it can be to live with any inherited condition, but the loss of vision is an especially big emotional and social trauma. That's why I decided to further my studies in this field."

Stéphanie agrees: "I became more aware of how special and wonderful it is to be able to see things and how disrupting and challenging it must be to have to let go of that. Being able to clarify what goes wrong in retinal disease is a big motivation, both because it gives patients an idea about what's going on in their eyes and what might happen in the future, and also because it might eventually help develop therapies."

Mubeen and Stéphanie each focus on different areas of the project. Stéphanie uses computer software to help her narrow down and combine vast amounts of genetic information, part of a discipline known as bioinformatics: "When the usual methods have failed to identify a mutation that explains someone's sight loss, I look at all the variants in the DNA, which number well over 100,000. Most of these variants are benign and normal and it's quite a challenge to find those one or two that

cause blindness. Computer algorithms can help me filter the data."

Mubeen is mainly involved in laboratory experiments to investigate the effects of newly discovered variants. "I'm looking for changes that may not directly affect protein structure but instead have an impact on the protein building process. I test the variants to clarify their role in disease progression."

"Without patients we can do nothing"

Neither Stéphanie nor Mubeen could make progress without the contribution of people living with Stargardt disease. "It's the most important pre-requisite for any study" Mubeen tells us. "Without the contribution of patients we can do nothing. By studying their genetics we can really understand the underlying mechanisms of disease, which will ultimately benefit so many people because it allows us to look for treatment options." *See page 18 for more on the development of treatments for Stargardt disease.*

With your support, we can continue to support young scientists like Mubeen and Stéphanie who are solving the puzzles of inherited sight loss and working towards treatments. For more information about Prof Cremers' project and other studies funded by Retina UK, visit www.RetinaUK.org.uk/research/research-we-fund.

O X S I G H T



James Laird is a fiction writer and an avid traveller, having visited upwards of twenty different countries. Sadly, as each year passes, his vision has decreased.

James lost his sight due to a degenerative eye condition called Retinitis Pigmentosa.

But with OXSIGHT glasses in tow, James is excited about journeying around the world again.

"I'm hoping to continue my travelling adventures. I've been to about 23 different

countries now. All those kind of limitations and all those ideas of 'I wont be able to' or 'I shouldn't be able to' or 'I cant be able to' are gone. That's an area that it will help with."

"I'm planning on hiking the Grand Canyon, I'm planning on doing something in Nepal and seeing some of the mountains there, or maybe going to South America and learning Spanish for the first time would be something that's incredible."

OXSIGHT smart glasses can enhance the remaining sight for individuals with a visual impairment, such as conditions that cause peripheral vision loss, for example Glaucoma, Diabetic Retinopathy, Retinitis Pigmentosa, Myopic Degeneration, and other degenerative eye diseases. They have also helped people with a visual impairment caused following a stroke, such as homonymous hemianopia.

Visit our website to find a local event to you www.oxsight.co.uk

To book a **free demonstration** with one of our opticians, please contact us:

01865 580255 · care@oxsight.co.uk · oxsight.co.uk

O X S I G H T

OXSIGHT smart glasses can enhance the remaining sight for individuals with a visual impairment, such as conditions that cause peripheral vision loss. They have also helped people with a visual impairment caused following a stroke, such as homonymous hemianopia.

19 March - Bury Blind Society Demo Day, Bury

24 April - Sight Village, Sandy Park Stadium, Exeter

30 April - Sight Concern Technology Day, Worcestershire

6 May - Demo Day, New College Worcester, Whittington Rd, Worcester

15 May - See & Hear Shropshire, Shrewsbury Sports Village, Harlescott

16 May - Sleadford Social Eyes, Town Hall, Sleadford

17 May - Future Vision Day, Kendal Town Hall, Cumbria

22 May - South Lincolnshire Blind Society Demo Day, Boston

23 May - South Lincolnshire Blind Society Demo Day, Grantham

30 May - EYECAN 2019, Town Church House, Jersey

To book a **free demonstration** with one of our opticians, please contact us:

01865 580255 · care@oxsight.co.uk · oxsight.co.uk

Developments for Stargardt disease treatments

Researchers funded by Retina UK have contributed to the early development of potential new treatments for Stargardt disease, with their findings recently published in the journal *Genetics in Medicine*.

Stargardt disease principally affects central vision, with onset usually occurring during adolescence or young adulthood, and is frequently caused by errors in a gene known as *ABCA4*. However, in many cases, no faults can be found in the sections of the gene that code the building block 'ingredients' of the *ABCA4* protein, meaning that there are no clues to guide scientists in the development of treatments. Profs Frans Cremers and Rob Collin, at Radboud UMC in The Netherlands, are leading a team searching for hidden mutations in these cases.

A regular genetic test only examines part of each gene, disregarding non-coding sections known as 'introns'. These sections are 'edited out' during protein construction by a process known as splicing. However, mutations within introns can still have a significant influence on how the coding regions are edited and interpreted by the cell's protein-building machinery, often resulting in a faulty protein.

With the help of funding from Retina UK, thanks to your generous support the researchers have developed a fast, cost-effective method of scanning the entire length of the *ABCA4* gene, including the introns (*pages 14 and 15*). The team's new method has enabled them to find several intron mutations in cells from people living with Stargardt's and they have gone on to develop a kind of molecular patch, described as a "band aid", to cancel the harmful effects of these mutations.

"Errors in the DNA cause a disturbed function of the proteins in our eyes" explained Prof Collin. "With such a 'band-aid' we can block the mistakes, and by masking the mutations, the cells will eventually start producing good proteins again."

The band aid is made from a synthetic form of RNA, the molecule that acts as an intermediary to translate the genetic code in DNA into proteins. It is delivered to the retina via an injection into the eye. This RNA molecular patch approach has already proved successful for other conditions such as Leber's Congenital Amaurosis, where it is showing promise in clinical trials. However, each different mutation requires its own specific band aid, so obtaining a genetic diagnosis will be essential for those living with inherited retinal disease who may be able to benefit from these treatments in future.



Run for us

#TeamRetinaUK has had a fantastic start to the year with many of our runners achieving personal bests whilst running for Retina UK! If you'd like to join the team, we have access to places in events up and down the country, including:



Great North Run 8 September

We have five places in this iconic half marathon in Newcastle. One for the bucket list, it's a fantastic event which runners take on each year. Minimum fundraising target of £800. Sign up at www.RetinaUK.org.uk/greatnorthrun

Royal Parks Half Marathon 13 October

We have nine places remaining for this event, which goes through four of London's Royal Parks. Minimum fundraising target of £500. Sign up at www.RetinaUK.org.uk/royalparks

Join #TeamRetinaUK and you will receive:

- Support from a dedicated member of the Retina UK fundraising team
- A Retina UK running vest to wear on the day
- Retina UK t-shirts for your cheer squad
- A certificate celebrating your achievement when you've completed your challenge

If you have any questions please contact Emily on 01280 815900 or email emily.webb@RetinaUK.org.uk

"It gives me a chance to make a difference and raise awareness about people with serious eye conditions."

"I would highly recommend anyone to take on any challenge to raise money for this great charity."

Inaugural Professionals' Conference

Our first conference aimed specifically at health, education and social care professionals and volunteers who support those with inherited sight loss conditions will take place later this year.



The event will be free for professionals to attend and will take place at Kents' Hill Training Centre in Milton Keynes (MK7 6BZ) on Friday 27 September.

The event is open to Eye Clinic Liaison Officers (ECLOs), Rehabilitation Officers for the Visually Impaired (ROVIs), Qualified Teachers of the Visually Impaired (QTVIs), Mobility Officers, Clinicians, nurses and other medical professionals and volunteers who work with people with inherited retinal dystrophies.

Delegates will:

- Hear the personal stories of those affected by inherited retinal conditions, get an update on the latest research including genetic testing and counselling, the search for treatments and how patients can get involved in research
- Further their understanding of the conditions and the unique challenges

faced by those living with inherited retinal conditions

- Network with other professionals working in this area
- Speak with exhibitors, including our generous sponsors OxSight, and try out their products
- Learn how Retina UK can support professionals
- Understand what support/information/resources are available from other organisations.

If you are a professional we hope you will join us. If you are living with an inherited retinal dystrophy please share the details of this event with the professionals who support you.

Register now

Online: www.RetinaUK.org.uk/prof-conf

By email: info@RetinaUK.org.uk

By phone: 01280 821334

Could you spare a few hours?

Here at Retina UK we rely on our wonderful volunteers and we are always looking for more to join us!

We are currently seeking helping hands for a number of events. No specific skills are needed, just enthusiasm and a willingness to help. In return, you'll make a difference to your life and those around you.

London: London Marathon – Sunday 28 April

WE NEED: Team supporters and cheerers.

Newcastle: Retina UK Information Day – Thursday 16 May

WE NEED: Sighted guides and stand support.

Brighton: Retina UK Information Day – Tuesday 18 June

WE NEED: Sighted guides and stand support.

Milton Keynes: Retina UK Helpline Training Weekend – 28-30 June

WE NEED: Sighted guides and stand support.

Milton Keynes: Retina UK Annual Conference – Saturday 28 September

WE NEED: Sighted guides and stand support.

Bowness-on-Solway to Tynemouth (Hadrian's cycleway): Retina UK

Tandem Challenge – 12-13 October.
WE NEED: Team supporters.

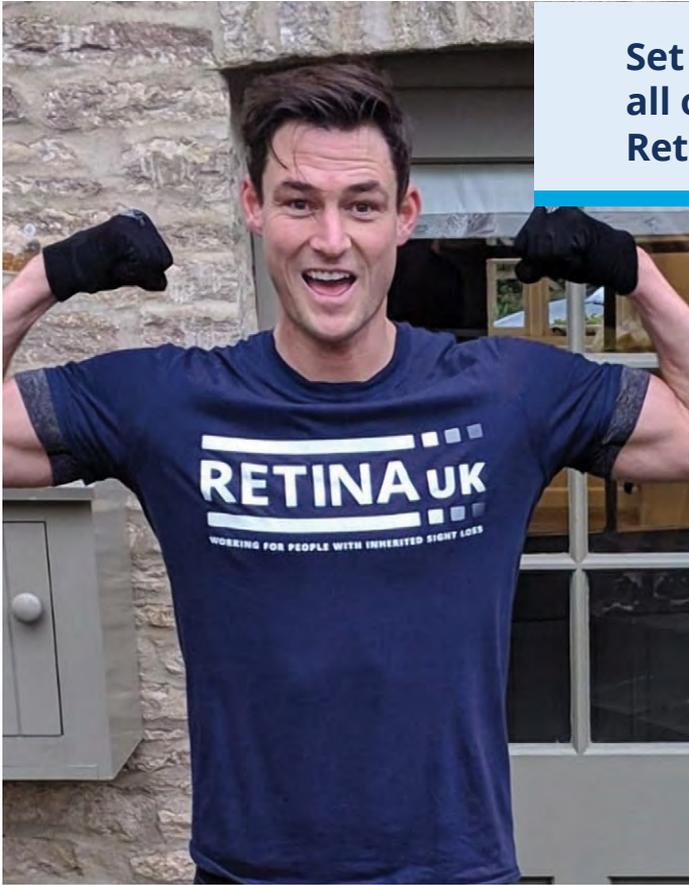
Belfast: Retina UK Information Day – Thursday 24 October

WE NEED: Sighted guides and stand support.

If you are interested in helping at any of these events, please contact Clair at clair.pudaruth@RetinaUK.org.uk or on 01280 821334.



Virtually running



Set your own distance and join runners all over the country taking part in the Retina UK Virtual Run.

Complete your run, in your own time, at your own speed, at your chosen location.

You can choose to complete your distance all at once or throughout the month of June. When you sign up you'll receive a Retina UK running vest, and when you've completed your challenge you will be sent a special Retina UK Virtual Running medal.

To sign up, go to www.RetinaUK.org.uk/virtualrun

Keep in touch

We are, as always, hugely grateful to our members and regular givers for their ongoing support. The money you donate allows us to plan effectively and invest with confidence in our information and support services and research.



You are an integral part of the Retina UK community and we value your input and feedback. We also want to make sure we stay in touch with you in the best possible way.

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First gene editing treatment moves towards clinical trials

The US Food & Drug Administration (FDA) has given the go-ahead for clinical testing of what could be the first gene editing treatment to be used in inherited eye disease.

The new treatment, known as EDIT-101, has been developed by US-based pharmaceutical company Editas Medicine and aims to use the relatively new gene editing technique known as CRISPR to treat Leber Congenital Amaurosis type 10 (LCA10).

LCA10 is the most common cause of inherited childhood-onset sight loss and is associated with mutations in the *CEP290* gene. While EDIT-101 is aimed at a specific gene fault, its development will help pave the way for the use of CRISPR in the treatment of a much wider range of retinal conditions.

EDIT-101 employs CRISPR to cut out the faulty part of the gene, thus restoring normal function and effectively 'rescuing' surviving photoreceptor cells from further damage. The hope is that this should arrest the progression of sight loss. You can find out more about CRISPR, and how it differs from more traditional gene therapy and other updates, in the research area of our website www.RetinaUK.org.uk/research.

The FDA has now approved Investigational New Drug (IND) status



for EDIT-101, which enables clinical trials to go ahead. Editas and its partner Allergan, which will take forward future development and commercialisation of EDIT-101, expect to enrol between 10 and 20 LCA10 patients with this specific *CEP290* mutation in an initial Phase I/II trial in the USA. The primary purpose of this small study will be to assess the safety and tolerability of escalating doses of EDIT-101, although any beneficial effects will also be assessed.

The CRISPR approach isn't the only one being used to try and tackle LCA10. In 2018 we reported on the involvement of Retina UK-supported researcher Prof Mike Cheetham in the development of a special molecule that 'silences' the effect of the *CEP290* mutation, rather than cutting the fault out of the gene. This alternative potential treatment, known as QR-110, is being developed by ProQR Therapeutics and has already demonstrated some success in early phase clinical trials.

We are so grateful for all donations to our work



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