

LOOK FORWARD



Inside: The latest research news and details of our appeal to build the 'Gene Team' of tomorrow.

Did you join either of our Conferences this year? You can read about them inside this edition of Look Forward (pages 4, 5 and 7). We've had some fantastic feedback from our delegates so if you weren't able to attend, you can watch or listen to the recordings from the day on our website.

We've got a packed edition for you again. If there is anything you'd particularly like to see in this newsletter, please get in touch.

Please pass this newsletter on to others when you've finished reading it

The best days of the year

I'm still buzzing from our incredible Professionals' and Annual Conferences (pages 4, 5 and 7). Thank you to everyone who attended online or in-person. It was amazing to see so many of our community in-person in London. I tried to speak to you all, but I'm sure I didn't get to chat to everyone!



I'm pleased to tell you that our new website was launched in early June. Feedback so far has been really positive, with information much easier to find. Particular areas to highlight are our new Resources section ([RetinaUK.org.uk/resources](https://www.RetinaUK.org.uk/resources)) where you can filter content to find audio, video and written information. We also now have an event calendar ([RetinaUK.org.uk/events](https://www.RetinaUK.org.uk/events)) which can also be filtered based on the type, distance, location and date. Do come along to one of our

upcoming Peer Support Group meetings (pages 10-11) or take on a challenge for Retina UK (pages 18-19).

We have just launched our latest appeal to support the search for treatments for everyone. I know that the current economic situation is proving difficult for many but please do support us if you can. You can find out more on pages 22-23

or by visiting [RetinaUK.org.uk/appeal](https://www.RetinaUK.org.uk/appeal).

As always, if you have any questions, please don't hesitate to contact me. You can email me on chiefexec@RetinaUK.org.uk or call 01280 821334.

Tina Garvey, Chief Executive



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

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Retina UK is a Charitable Incorporated Organisation (CIO), registered charity number: 1153851

Articles for the Blind

Did you know we may be able to post this newsletter to you with no postage costs to our charity under Royal Mail's Articles for the Blind (AFB) scheme?



All you need do is notify us that you are blind or visually impaired and you are happy for us to send post to you under this scheme. Please email info@RetinaUK.org.uk or call us on 01280 821334 and ask us to record this information. If you already receive this newsletter from us marked Articles for the Blind, there is no need to do anything.

The money we save on postage costs will be invested in our information and support services and research projects.

Your newsletter, your choice of formats

Did you know that we produce this newsletter in a variety of different formats? You can choose from:

- Print (postage paid and Articles for the Blind scheme)
- Digital (Word and PDF)
- Audio (CD and memory stick)
- Braille

If you'd like to change the format you receive, just email info@RetinaUK.org.uk or complete the form at RetinaUK.org.uk/lf-preferences.

"It's great to have Look Forward in both print and audio formats as it means I can listen to the audio in the car with my family and share the information. The magazine is also great as we can enjoy the images too."

Lisa

Your feedback matters

We'd love to know what you think about Look Forward. Do you read it cover to cover or are specific features your favourite (e.g. the research articles)?

If you have any feedback about Look Forward, please email the editor, Jane Russell (jane.russell@RetinaUK.org.uk) or give her a call on 01280 821334.

Overwhelmingly positive feedback for our Annual



A big thank you to everyone who attended our Annual Conference on Saturday 24 June. We received more than 400 registrations this year, an increase of almost 60% from 2022. Thank you to our excellent speakers, exhibitors, contributors and sponsors, including the University of Westminster and our headline sponsor Janssen UK.

The day kicked off with a session about the importance of working in partnership. We involve our community and other organisations in our research, information and support, and awareness-raising activities because we know we have a greater impact when

we work together. It's clear you want to get involved because we have seen a significant increase in the number of people registering for our Lived Experience Panel ([RetinaUK.org.uk/more-info](https://www.retinauk.org.uk/more-info)) following this session.

We've had some great feedback about the technology of the future session, introduced by Glenn Tookey and Dr Robert Quinn. With so much investment and breakthroughs in navigation technology "The future is bright in terms of technology" according to Glenn.

Our afternoon was devoted to the



Conference



different areas of current research, including gene therapy, stem cell treatments, and synthetic implants.

This was followed by an ever-popular research Q&A session.



Conference recordings in both audio and video formats are available on our website: [RetinaUK.org.uk/resources](https://www.RetinaUK.org.uk/resources). If you would like to receive the audio recordings on CD or memory stick, please phone 01280 821334 or email info@RetinaUK.org.uk.

Thank you again to everyone involved for making our conference such a huge success.

"Once again, thank you for a great conference. I always feel a bit more optimistic about the future after attending your conferences. It is reassuring to know that research is in the hands of some extremely capable and enthusiastic people."

"I felt hesitant at first about attending my first meeting, but I am very glad I did. My husband joined me and was amazed by everything. We met lovely people; the staff made me feel very at ease and welcome. As for the speakers and researchers, they were amazing, caring and so passionate about helping others. I look forward seeing you at the next conference."

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Understanding 'lived experience' at our Professionals' Conference



The theme of our Professionals' Conference this year was understanding the lived experiences of people affected by inherited sight loss. It included a thought-provoking presentation from Dr Jasleen Jolly, who encouraged all of our delegates to be more empathetic when delivering news and try to always turn something negative into a more positive experience.

The highlight of the day was our lived experience panel, where members of our community, including the wider family, shared their own unique stories and perspectives. The session touched the hearts of many of our professional community and really highlighted the power of sharing personal stories.

'Difficult conversations and breaking bad news' continued the theme of the day with Professor Susan Downes and Dr Amanda Salisbury. "Your choice of words is so important. Approach the conversation in a way that is empowering. It can really can

make such a difference to the person receiving the news."

Conference recordings in both audio and video formats are available on our website: RetinaUK.org.uk/resources. If you would like to receive the audio recordings on CD or memory stick, please phone 01280 821334 or email info@RetinaUK.org.uk.

Thank you to all of our speakers, exhibitors, contributors and sponsors, including the University of Westminster and our headline sponsor Janssen UK.

"I was unable to attend in person, so thank you for giving the choice of online too. I have forwarded the recordings to my ROVI colleagues who missed the day. I would thoroughly recommend the Retina UK Conference. Excellent speakers."

"Absolutely fantastic and informative day. Looking forward to the next. I will also encourage eye clinic staff to attend."

Developing and testing approaches to treatment

There's still a huge amount of activity in laboratories and at clinical trial sites around the world, developing and testing innovative approaches to treatment. Here's a snapshot of results from the first half of the year:

OCU400 from Ocugen

Biotechnology company Ocugen has announced positive preliminary safety and efficacy results from its phase 1/2 trial in adults with RP and LCA caused by faults in the NR2E3 and RHO genes. Ocugen's therapy, known as OCU400, is a novel gene therapy approach that doesn't just target one specific genetic cause. Instead, it relies on providing copies of a "modifier gene" that can influence the expression of multiple genes and gene networks. It could potentially be used to treat sight loss with a wide range of genetic causes.

The early results (based on the effects seen in seven trial participants) suggest that the treatment is safe. OCU400 also appeared to improve or stabilise participants' ability to navigate a maze in low light.

Ocugen has now widened the trial in the USA to include adults affected by Leber congenital amaurosis (LCA) caused by the CEP290 gene, and children affected by mutations in NR2E3, RHO and CEP290. The company will continue to monitor participants before deciding

whether to proceed to a phase 3 trial.

EA-2353 from Endogena Therapeutics

Meanwhile, Endogena Therapeutics is also exploring an innovative approach that could have broad applicability. They have developed a drug that can potentially activate retinal stem cells lying dormant in the eye. These cells could then develop into mature photoreceptors to support some restoration of vision.

The treatment, currently called EA-2353, is at the first stage of clinical testing, which will primarily establish its safety. This study involves 14 people with RP in the USA, who are receiving the drug via injection into the eyeball. Early data suggests there are no serious side effects.

Transcorneal electrical stimulation from OkuVision

Another approach that could be appropriate for a large proportion of the Retina UK community is transcorneal electrical stimulation, which involves a device rather than a drug, and relies on the theory that electrical stimulation may induce a neuroprotective effect on retinal cells. This is being explored by German company OkuVision; their OkuStim device includes electrodes that are placed on the lower eyelid and can be used at home, after training from an ophthalmologist.

OkuStim was trialled several years ago

at University Eye Hospital Tübingen (Germany) in around 50 people with RP, demonstrating good safety. The results of that study have recently been reanalysed, and suggest that OkuStim can slow visual field loss. OkuStim is currently undergoing a much larger trial within the German health service, and this study should provide definitive evidence, as to whether the treatment can have a significant effect. If so, OkuVision hopes to persuade the NHS to make OkuStim available in the UK.

OkuStim is not the same as Fedorov Restoration Therapy – listen to our recent podcast to find out more: RetinaUK.org.uk/resource/podcast-unproven-treatments.

Condition-specific research

Leber congenital amaurosis (LCA)

There have been a couple of exciting findings in the laboratories of researchers investigating LCA caused by faults in the CEP290 gene. US researchers found that an old blood-pressure drug called Reserpine appears to support photoreceptor survival in cell and animal models. They also found four other promising drug candidates in a screen of around 6,000 compounds previously approved to treat other conditions. This 'drug repurposing' approach is an efficient and cost-effective way to find new treatments.

Meanwhile, here in the UK, former Retina UK grantee Prof Mike Cheetham

and his team at UCL found that a plant-derived substance called eupatilin, belonging to a group of compounds called flavonoids, improved aspects of photoreceptor structure in a number of cell-based models of CEP290 LCA.

Stargardt disease

Intergalactic Therapeutics has announced that it has made progress in developing a gene therapy to deliver healthy copies of the Stargardt's gene, ABCA4, into the retina. Like a number of other retinal disease genes, including USH2A, ABCA4 is very large and doesn't fit inside the virus-based packaging systems most commonly used for gene therapy. Intergalactic Therapeutics has successfully used a non-viral system to deliver gene therapy in animal models. The company now intends to gather the data it needs to enable it to apply for permission to begin studies in humans.

Pharmaceutical company Belite Bio is testing a new orally administered tablet, which aims to address some of the damaging toxin accumulation that occurs in the retina in this condition. Results from Belite Bio's phase 2 trial are encouraging, with the drug appearing to be safe, and almost 60% of study participants showing reduced progression of their disease. A phase 3 trial is now underway.

You can keep up to date with developments via our e-news, Look Forward magazine, website, webinars and podcasts.

Make new connections in your area



Our Peer Support Group meetings are active around the UK. Some meet in person, while others meet online. Our National Peer Support Group recently hosted Paul Ashurst, founder of AbleNet Ltd, who spoke about why he set his company up and how visually impaired people can enjoy an experience day.

Members of our community talked about their experiences of using AbleNet's services: "When I was 8 years old I got to sit in the cockpit of a Boeing 747 and had a dream to one day be able to fly a plane. Sadly that dream was short lived as only a couple of months later I was diagnosed with retinitis pigmentosa. Knowing that I would never be able to sit behind the wheel of a car, let alone pilot my own plane, was a bitter pill to swallow.

"I was introduced to Aerobility through AbleNet where I got to fly a Piper Warrior for a 40th Birthday gift. The experience was amazing; I got to take off myself and climb to 2,500ft. It was something I thought I'd never get to experience and I'm so grateful that there are companies that work in partnership to offer experience days to the visually impaired."



"A few years ago I was given a supercar driving experience on a disused airfield in Oxfordshire for a birthday present.

“The big day came and I slid into the very low driver’s seat and an experienced supercar driver took his place next to me and explained all the controls including the steering wheel gear change paddles, which felt so comfortable to use. I started off driving slowly and after a quick talk on how to drive the simple circuit, the instructor gave me the OK to go and off I went down the straight with my foot to the floor. The acceleration was phenomenal! I got up to 150mph, which amazed me.

“The day was arranged exclusively for people with visual impairments and I learnt afterwards that the organisers particularly enjoyed these sessions. The experience was all that I could have hoped for.”

If you are interested in taking on an experience day, please visit ablenet.co.uk and use voucher code 10retinauk2023 for 10% off all Supercar products. Find out more about our Groups at RetinaUK.org.uk/groups.

Webinar:

**Ask the expert with
Samantha de Silva**

28 September – 7.00pm

Our ‘Ask the expert’ webinars are a great opportunity to get your questions answered by an ophthalmic professional.

This time we will be joined by Samantha De Silva, a consultant ophthalmic surgeon specialising in medical retina disorders at the Oxford Universities Hospital Trust.

Samantha has joined us previously at conferences and other events and is experienced at providing information and answering questions in an easy to understand way.

Register to attend at RetinaUK.org.uk/webinars.



“It was great chatting to the group over a lovely lunch followed by an ice cream after a leisurely walk around the park.”

Hampshire Group members enjoying themselves at the Royal Victoria Country Park, Southampton

“Our volunteering is in safe hands”

Steve has been volunteering for Retina UK since its formation in 1976 and has been a part of the Helpline team since the early 1980s. He was part of what was then known as the ‘National Welfare Committee’, which introduced the Helpline. He said: “I just felt that it was important to help and support people who have just been diagnosed.”



Steve is living with a Rod-Cone Dystrophy, one of many inherited sight loss conditions. He was registered blind at the age of 20, completely lost his sight at the age of around 50 and is now in his 70s, still volunteering regularly on the Helpline.

Steve remembers very well a caller named Khadeja, who called the Helpline multiple times, following her diagnosis with RP in 1999. Khadeja said “I was in a terrible state, but they were always so understanding and they always listened and were patient with me, despite the fact that I called so many times over that initial period”. She went on to say “It made such a difference having someone to talk to. I was so upset and services like Eye Clinical Liaison Officers (ECLOs) just didn’t exist at that time. Just speaking to the Helpline team, knowing they are living with sight loss but are able to live

confidently and do everyday things, it was so reassuring. I felt like I could actually face the future.”

Khadeja went on to join the Helpline team in 2017. She said “I remember the support I got from Steve and the other volunteers and the kindness they showed me and I wanted to do something similar for someone else, to give back.” Steve describes it as “Going full circle from being a service user to volunteering on the Helpline.”

They both said what a thrill it was to meet each other in person at the Retina UK volunteer training weekend in 2019. They love volunteering for Retina UK and being able to offer support to others and signpost information and services available to them.

“Our volunteering is in safe hands” according to Steve.

Volunteer Impact Report

For the first time we have produced a Volunteer Impact Report based on the feedback we received from our volunteer team in our three-yearly survey. Last year 100% of volunteers who completed our survey told us Retina UK supports them 'very well' in their role and 100% said they were 'very satisfied or satisfied' with their volunteering experience.

For the full report visit our website: RetinaUK.org.uk/resource/volunteer-impact-report.

"... being part of a team that completely understands my condition without explanation is hugely important. It is very powerful and satisfying."

Volunteers' Week

Volunteers' Week between 1-7 June is always the time to say a big THANK YOU to all our volunteers for the incredible work they do and their immeasurable value to Retina UK. We celebrated our volunteers via social media this year; here are some highlights.

- In 2022 our helpline volunteers answered over 750 calls and replied to over 200 emails giving around 400 hours of their time each month to the Helpline service.
- Volunteers in our Peer Support Group network enabled around 600 people living with sight loss to meet others like themselves in their local area.

To all our volunteers, thank you for being a vital part of making Retina UK what it is: an understanding, supportive organisation providing invaluable support of those affected by inherited sight loss when they need it the most.



Rachael who lives with Bardet Biedel syndrome and is a local group facilitator: *"Volunteering gives me a purpose, it helps my mental health. If I can help one person in my group, then I've achieved something."*

David lives with RP and is a long-serving Helpline and Wellbeing volunteer: *"It's a privilege to volunteer. I'm always grateful for what the organisation has given to me and it's logical to give back to you, so thanks."*

Thank you ^{#TeamRetinaUK}

Our incredible supporters have been raising money for Retina UK through lots of races and challenge events! Without #TeamRetinaUK, we wouldn't be able to do what we do. Here's just a handful of supporters who have been taking on fundraising activities recently:



Helen and Matt Judge took on the Manchester Half Marathon for us. We are so grateful for your support.



Silvia Anghel raised an incredible £722 after taking on the Edinburgh Marathon. Thank you for your support!



Edward Shelton-Richards raised a phenomenal £885 at the Edinburgh Marathon in May! Thank you to Edward and everyone who sponsored him.

Thank you to Rachael King for choosing to support Retina UK with a £100 donation from family and friends in lieu of birthday presents again this year.



Thank you to Barbara Watt for organising coin collection tins at the C&M DIY Centre, raising over £105 so far this year.

Father and son Martyn and Ben Cox celebrated their milestone birthdays in style, holding a joint birthday party on their farm. Guests were asked to donate to Retina UK instead of buying birthday presents and raised an amazing £1,070. Thank you.

Thank you to everyone who has fundraised for Retina UK over the last few months.

TCS London Marathon



After four years, the TCS London Marathon was back to its traditional springtime slot. Race day was superb, as #TeamRetinaUK joined the thousands of runners taking part in the Marathon, encouraged by the cheering crowds, including family and friends, who gathered to line the pavements on the 26.2 mile route. Our magnificent team, both in London and elsewhere, raised over £35,000, for Retina UK.

A huge thank you to our 2023 #TeamRetinaUK: Alan, Alex, Amy, Bradley, Christian, Jonny, Kerry, Leanne, Matt, Greg, Richard, Signe, William, Shawn, Balini and Jane-John, and to all your family, friends and colleagues who supported you – we are enormously grateful to you all.

If you are interested in taking on the London Marathon in 2024, we'd love to hear from you. Please contact our new Events and Community Fundraising Manager on James.Clarke@RetinaUK.org.uk or visit RetinaUK.org.uk/london.

Hopefully to SeaView



Well done and a huge thank you to the Isle of Wight, Local Group, and their family and friends, for taking part in the Hopefully to SeaView sponsored walk on 11 June, raising £5,954. This year is the 5th anniversary of the Hopefully to SeaView sponsored walk, organised by Colin McArthur and his wife Linda. We are incredibly grateful to Colin and Linda, and to everyone who took part in the event.

If you are a member of a group who could be interested in a fundraising event, please get in touch with the Fundraising Team on fundraising@RetinaUK.org.uk or call 01280 815900.

Please share your photos with us at fundraising@RetinaUK.org.uk or tag us on social media.

Hope for the future

Colin McArthur experienced severe anxiety and depression in his teens when he first received what he describes as the devastating news that he would probably go blind because of a diagnosis of retinitis pigmentosa (RP). He still worries that his grandchildren and future generations in their family may also be carriers of faulty genes. In this article, we hear his story and the reasons why he has hope for the future.

Colin grew up in south west London with one brother who still has perfect vision. He fondly recalls watching his beloved Fulham F.C. play at Craven Cottage in his early years. He also loved collecting stamps and vividly remembers the exciting journey on the ferry over to Belgium every year to spend five weeks of his summer holidays with his relatives from his mother's side of the family.

Even from a young age, Colin says it was obvious he was experiencing some problems with his sight. When asked to do sketches of his nursery classroom, he only drew what he saw in front of him, completely missing the sides and the ceiling. On cinema visits, he saw very little, mainly lighting. He was given glasses and his parents explained it was short-sightedness, and he says he just about managed

to 'plod along'. He could cope with playing football at high school, but was unable to follow the flight of a tennis ball. Eventually, he visited Moorfields, where he was diagnosed with glaucoma. However, he went to Ghent soon after on the advice of his Belgian relatives, and was diagnosed with glaucoma and RP.

At first, Colin says he was distraught when taking in the reality that eventually he would probably lose all his vision. He began to shut himself away from his family and friends, and just listened to records on his own in his room. He describes how he felt 'terrified' and made excuses not to go out with his friends.

In 1971, Colin met Linda at work, who he would later marry and have five sons with. His eye sight deteriorated further in the 1980s and he found it harder to read and do his job, Colin says this again caused great anxiety and fear over losing his job and being able to support his family. This is when he boldly decided to start fundraising to help people going through similar experiences, and who needed support there and then.

While Colin is convinced it's so important to support our community today with information and support services, he hopes for a day when cures will be found for retinitis pigmentosa. That's why, in addition to his incredible fundraising efforts



on the Isle of Wight where he lives, he feels passionate about leaving a legacy in his will, so that ground-breaking medical research carries on until the day our community need no longer fear losing their sight. Then all his fundraising efforts, like so many others, will no longer be needed.

Have you considered leaving a gift in your Will for Retina UK so we can continue to fund vital medical research projects? Why not contact our Trusts and Major Gifts Officer Mithun on 01280 815900 or by email at mithun.dasbhaumik@RetinaUK.org.uk to find out more?



The complete group who took part in the SeaView sponsored walk (see page 15)

We're here to support you every step of the way

Take on a fundraising challenge for Retina UK. You'll help support people affected by inherited sight loss to lead better lives today and accelerate the search for treatments for the future. Whether you want to take on a run, a walk, a trek, a cycle ride, a skydive or something else, we will be here to support you every step of the way to help you meet your fundraising goals.



We work with lots of challenge event providers so if you have an idea that you want to make a reality, we'd love you to get in touch with our new Events and Community Fundraising Manager, James Clarke, who has recently joined the charity. James lives with retinitis pigmentosa, and has raised over £105,000 for Retina UK since 2016, before joining the charity as a member of staff in May 2023.

James would love to hear from you: Email james.clarke@RetinaUK.org.uk, call 01280 815900, or contact the wider Fundraising team on fundraising@RetinaUK.org.uk.

To find out more about the events that we currently offer, visit our website: RetinaUK.org.uk/challenge.

"Raising money for Retina UK following my diagnosis has turned a negative thing into an amazing positive experience for me. The first year was hard, but now I'm so at peace with it. It's changed my life. I've had so many fantastic experiences. I've met some incredible people and it wouldn't have happened without it!"

James Clarke



run

First time runner or seasoned pro? Join us for a top race including the London Landmarks Half Marathon, 2024 TCS London Marathon, Great North Run, Royal Parks Half and more!

RetinaUK.org.uk/run



walk

Whether you fancy coastal paths or riverside rambles, sign up to a 25, 50 or 100km Ultra Challenge Trek:

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The power of collaboration:

Uniting charities on social media for a greater impact

In today's interconnected world, social media has become a powerful tool for promoting causes, raising awareness, and mobilising support. Recognising this, we have joined forces and collaborated with other charities to amplify our voice, expand our reach, and make a lasting impact.



By speaking out, either as individuals or collectively, we can raise awareness of the impacts of sight loss and educate the public to enhance their understanding. In turn we can change preconceptions, attitudes and behaviour. As part of this, in January, we took part in a social media day of action under the banner of #SupportCantWait to emphasise that the rising cost-of-living disproportionately affects blind and partially sighted people.

Alongside 67 other sight loss and disability charities, including RNIB, RNID, Sense, Scope, Blind Veterans, Thomas Pocklington Trust and Visionary, we called on the Government to address the long term factors which have led to blind and

partially sighted people, and disabled people, entering the cost of living crisis at a major disadvantage.

We invited supporters and community to join in, and share content about the cost of living on Twitter using the hashtag, #SupportCantWait. The campaign reached 2.5million people.

The second call to action followed the same structure, and went out in April, emphasising the need for further support as the new financial year begins. The campaign was successful in terms of its impact, with a total reach of 1.5million.

The group continues to meet to discuss further campaigns we can collectively work together on.

Funding the best teams to find treatments quicker



For 47 years, Retina UK has funded the best science, searching for genes and treatments for everyone living with inherited retinal dystrophies (IRDs). Support the search for treatments for everyone; join our campaign to build the ultimate 'Gene Team' of tomorrow!

In recent years there has been a huge acceleration into different treatment approaches for IRDs and the underlying causes of progressive sight loss. It's an incredibly exciting time, but we need to keep the momentum going.

Nurturing a new generation of scientists is vital to the future of retinal disease research. We have recently teamed up with the Macular Society to fund a record three PhD studentships. These early career scientists will take the baton of sight loss research into the future.

- Prof Jacqueline van der Spuy (UCL Institute of Ophthalmology) will supervise a student to explore the use of prime editing to correct the most severe mutations causing

Stargardt disease;

- Prof Omar Mahroo (UCL Institute of Ophthalmology) will lead a study to better understand how specific visual symptoms are linked to the diagnosis and prognosis of macular degeneration;
- Dr Roly Megaw (Edinburgh University) will supervise an investigation of how particular mutations in the RPGR gene impact cone photoreceptors.

With your support we can fund even more scientists and even more research. Please give what you can. Call our friendly team on 01280 821334, complete the form at the back of this newsletter or visit [RetinaUK.org.uk/appeal](https://www.RetinaUK.org.uk/appeal).



After being alerted to the fact that some people living with Stargardt disease experience flashing lights in the visual field, while others experience discomfort associated with light, we started to more consistently ask patients directly about it and were surprised as to how prevalent these symptoms are. We are therefore investigating this more systematically, to see how many patients are affected, and whether there are particular patterns and associations with particular stages in the disease. We hope this work will enable us to better understand these symptoms and what underlies them. This will improve our understanding of the condition, and in turn allow us to better inform patients about what they might experience, as well as opening avenues for research into potential future treatments.

Omar Mahroo



This funding will enable us to use state-of-the-art technologies to understand whether it will be possible to rewrite the genetic code in patients suffering from Stargardt's disease. In doing so, this would permanently 'repair' or 'correct' the genetic change that causes the disease within the affected cells of the eye, thereby permanently curing the disease. However, there are numerous challenges that will need to be overcome to ensure that this can be done in a safe and effective manner, and the main objective of this project is to explore whether it can be achieved in a three-dimensional retinal organoid that models the light-sensing tissue of the eye.

Jacqueline van der Spuy



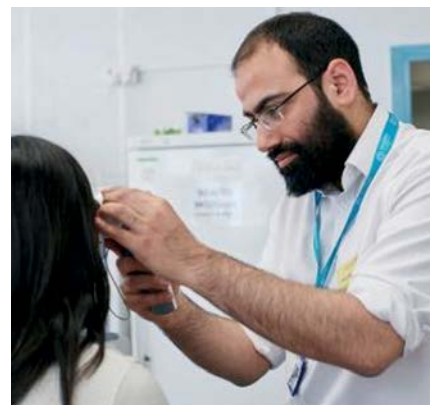
A proportion of patients with mutations in the RPGR gene develop early loss of central vision due to the mutations affecting their cone light sensing cells. This often occurs at a young age and causes significant visual loss. Unfortunately, any gene therapy targeting the rod light sensing cells for RPGR disease would not help these patients and so we need to develop alternative strategies. This funding will allow us to better understand what goes wrong in cone cells when RPGR is mutated. It is hoped that by doing so, we might identify targets for treatment.

Roly Megaw



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