RETINA UK

LOOK FORWARD

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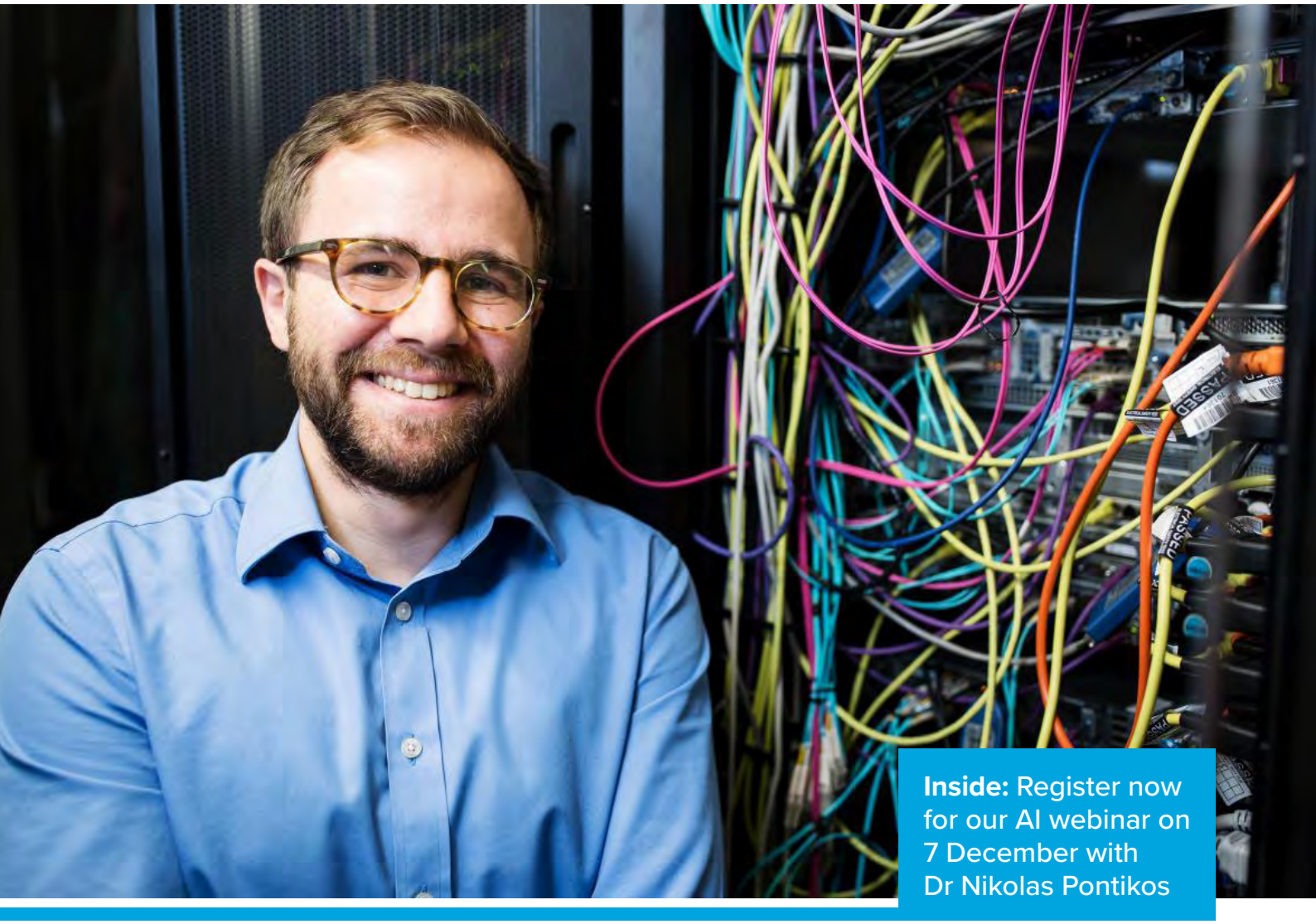

Inside: Register now for our AI webinar on 7 December with Dr Nikolas Pontikos

This edition of Look Forward includes some great features, including the latest research, Charles Bonnet Syndrome, The Blind Poet, Dave Steele, and much more. As always, we'd welcome your feedback and any suggestions for articles you'd like us to include in the next edition. Email **info@RetinaUK.org.uk** or call us on 01280 821334.

Reflecting back and looking forward

Is it too early to mention the C word? Yes, Christmas is just around the corner and we're delighted to once again be taking part in The Big Give Christmas Challenge. During the week of The Big Give, online donations via The Big Give website, are doubled, at no extra cost to you. See page 17 for more information.

This is the last edition of Look Forward for 2023, so I have been reflecting back on what has been a very busy year, the highlight of which (for me) was our Conferences in July. It was great to see so many of our community getting together, sharing in the latest research and making connections with each other. If you would like to watch or listen to the recordings, they are available on our website **RetinaUK.org.uk/resources**.

We hope to be announcing our latest innovative research funding very soon. It will be communicated in our e-Newsletter and on social media. If you don't currently receive our e-Newsletter, you can sign up by calling our office on 01280 821334 or emailing **info@RetinaUK.org.uk**.

Finally I'd like to thank our supporters, donors, volunteers and trustees for all of their contributions in 2023. We simply couldn't do what we do without you.

Merry Christmas!

Tina Garvey, Chief Executive

This newsletter has been funded through sponsorship by Janssen. Janssen has not been involved in the production, review or distribution of this material.

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

Harnessing the power of AI

Our final webinar this year features Dr Nikolas Pontikos, who will introduce the subject of AI (Artificial Intelligence) on Thursday 7 December at 7.00pm.

Nikolas is a bioinformatician, who uses computer power to tackle medical research challenges. He will be talking about his project to develop AI to identify the genetic cause of an inherited retinal condition from scans, without the need for a genetic test, along with other ways that AI can help us understand eye disease.

If you would like to attend, please register at **RetinaUK.org.uk/artificial-intelligence**.

If you have missed any of our webinars, recordings (in video and audio only format) are all available on our website **RetinaUK.org.uk/resources**.

Recordings are also available from our 2023 Conferences.

If you don't already receive our e-Newsletter, which is sent monthly (except for the months when Look Forward is published) please get in touch and we'll add you to our mailing list. You can call us on 01280 821334 or email **info@RetinaUK.org.uk**. The e-Newsletter is sent via email and is also available in plain text and audio formats.

Our Webinars in 2023

- **Supporting Retina UK and what it can do for you**
- **Ask the expert with Simon Keightley**
- **Low vision services, aids and equipment**
- **Getting involved with Retina UK, the value of volunteering**
- **Hair care and styling with Anna Cofone**
- **Ask the Expert with Samantha de Silva**
- **Support through Access to Work**

Searching for the cause of Charles Bonnet Syndro

Researchers are continuing to try to establish the cause of Charles Bonnet Syndrome (CBS), a well-documented condition that causes visual hallucinations. These hallucinations can feel very real to the person experiencing them and can be very distressing.

Charles Bonnet Syndrome is common in adults and children who have lost over 60% of sight, including those who live with inherited sight loss conditions. Researchers believe that CBS is caused by someone's brain reacting to their loss of vision but they don't currently understand why some people experience it, whilst others don't.

Recent studies include a team in Oxford, who have been comparing brain scans of people who experience CBS with those who don't. Meanwhile a team at Anglia Ruskin University is studying electrical activity in the brain during hallucinations.

Dr Jasleen K Jolly, Associate Professor, Vision and Eye Research Institute, Cambridge has kindly provided a short update:

"I would like to start by saying thank you to all the people who have taken part in the research studies taking place across Oxford and Cambridge.

"Traditionally CBS has been associated with older age. Our prevalence work is showing this is not the case and

> ***"I have amazing hallucinations of teacups, of flying saucers, orbs and strobe lights. Some people can find it very, very disturbing, but mine are actually quite humorous."***
>
> *Perm Bhachu, West Midlands Local Peer Support Group Facilitator*

me

Images by Jeremy Webb Photography.

it can occur at any age. It can also occur when vision is reduced in one eye, or the vision loss is temporary. We are trying to explore if there is any relationship between age, severity of vision loss and the hallucinations.

"We have also been using brain imaging and electroencephalogram (EEG) to understand the changes in the brain. The aim is to understand why some people experience CBS and others do not. We have finished collecting the data and are now analysing it."

What people see can vary from shapes, patterns and colours to vivid images of people, animals or objects.

Awareness of CBS is growing, thanks in part to the portrayal of characters with the condition on television. It is however important you tell your doctor if you are experiencing hallucinations so that they can rule out any other conditions.

There is no cure, or specific medication proven to treat CBS, but there are things you can do to help. Simply talking about what you are experiencing with others may make it easier to cope.

Information and support

If you live with an inherited sight loss condition and experience CBS, Retina UK can arrange for you to speak to someone with lived experience. Email **services@RetinaUK.org.uk** or phone our helpline and ask for a referral 0300 111 4000.

Leading expert on CBS, Professor Dominic Ffytche, presented a webinar for Retina UK, which included potential coping strategies. The recording is available on our website (in video and audio only formats): **RetinaUK.org.uk/resource/cbs**.

THANK YOU

#TeamRetinaUK

Kate Flanagan took on the Manchester Half Marathon in October, raising over £2,200 in the process!

Sarah Cherry and Donna Farmer took on the Yorkshire Three Peaks in July and donned their Retina UK t-shirts during their training hikes!

Andy Houghton took on our new Bonfire Night Skydive campaign and raised over £1,000

Thank you to James Clarke's team of 15 who took on the Yorkshire Three Peaks (and all weather conditions!) in July and raised over £6,500 for Retina UK.

Our annual Great Bake campaign has returned this autumn. We'd like to thank Gwyneth Bowes for raising £265 and Luke Fanshaw and his colleagues for raising £100.

Tomos Gwynfryn conquered an Ironman in Swansea and raised over £500! Thank you Tomos

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

Alex Houlding completed the Royal Parks Half Marathon in October and raised an amazing £1,300 for Retina UK. Simon Hill also took part in this race and raised over £1,200!

Last month, Juste Tuzikaite took on an Ultra Marathon (33 miles!) for us, at the beautiful Ladybower Reservoir in Yorkshire!

Georgie Turner found her recent Triathlon “one of the best days of my life” and raised an incredible £700 for Retina UK!

Thank you to everyone organising fundraisers in memory of Finlay Macleod, including the Bristol Jets event that raised over £65, the University of Bristol rugby match that raised over £500 and Rosslyn Park’s BBQ that raised over £1,500.

If you are thinking about taking on a challenge in 2024 for #TeamRetinaUK, we would love to hear from you. We have a wide range of events on offer, from runs, to treks, to skydives and we are here to support you every step of the way. If you have any ideas or queries, please get in touch with our 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.

“Everything happens for a reason”

The Blind Poet Dave Steele is living with retinitis pigmentosa. He talks about his sight loss journey so far and the inspiration for his amazing poems.

“I was told as a child that we have retinitis pigmentosa (RP) in my family and to just get on with my life and not really worry about it too much. That’s exactly what I did. After I left college I started work as a singer, firstly as a blue coat for Pontins then a cabaret singer, working on cruise ships. I spent most of my 20s enjoying my life, travelling all over the world.

“Things changed for me in my late 30s. I went for a routine eye exam and the optician told me there had been a big change since my previous visit. I was referred to a retinal specialist and two weeks later was declared severely sight impaired.

“The following eight or nine months were difficult. I could no longer drive so I wasn’t able to continue my job with a garage or do my singing gigs. I applied for every bit of help that I could possibly get, but there was a long delay for Personal Independence Payment (PIP) applications. I was also struggling with anxiety and depression, not just because of my sight, but also because of the financial pressure it was putting on my family. I felt terrible. I remember for those first eight or nine months not actually leaving the house without my wife because I was so anxious.

“But life shows us a path. When I was at my lowest and really struggling to go out on my own, I was invited to a support group in Newcastle. The organisers heard that I was a singer and asked me to sing some songs. The night before I was going over ideas and I thought it would be really cool if I could take a song that everyone

knows and change the words to talk about living with low vision, blindness and RP. So I chose Stand By Me, by Ben E King. The opening line “when the night has come, and the land is dark, and the moon is the only light we’ll see” described night blindness to me. I rewrote the lyrics, and instantly when I performed that song, the room changed. People were coming up to me afterwards, some of them quite emotional, shaking my hand saying that the words that I had written helped them feel like they were less alone.

“So fast-forward 10 years. I’ve written over 3,000 poems and counting as well as several books. Before I was diagnosed with RP, I went through many years of really struggling emotionally. I had some times in my life when I was homeless, some suicide attempts and really struggling with mental health. One of the things that living with RP has taught me is that everything happens for a reason. The things that we go through give us the tools to face the future.”

Dave’s books are available on Amazon and other book retailers. Calibre Audio also plans to make them available in audio format. A recording of his talk to our West Yorkshire peer support group is available on our website: **RetinaUK.org.uk/dave-steele**.

The Stranger, by Dave Steele

Today, a stranger asked me what has blindness done to me?

Has it limited the plans I’ve made or the things I hoped would be?

Has it forced me now to settle on a life that’s second best?

Has it made me give up lots of things since I failed the blindness test.

Do I still have aspirations, special places, dream to go?

Is there any point in beauty? If the eyes don’t work to show

But my answer came so quickly, not a thought considered twice.

I am happy for this blindness for the way it’s changed my life.

It has taught me what’s important, showed me who my real friends are. And I wouldn’t change the things I’ve learned just to get back in my car.

I have met amazing people since this blindness took my sight. We share in common struggles, joined together through this plight.

Though my retinas are dying, my mind’s vision has increased.

For each day I’m making memories, for long after sight has ceased.

So never offer pity for the broken sense I’ve lost. For I feel I have gained more than the price that blindness costs.”

Therapy development updates

There are many ongoing clinical and laboratory studies around the world, exploring innovative approaches to treating inherited sight loss. Here's a snapshot of a few recent news stories:

Repurposing chemotherapy

Biotechnology company Aldeyra has announced that its drug ADX-2191 met the primary goal of safety in a small clinical trial in retinitis pigmentosa (RP), and led to some improvements in trial participants' retinal function. ADX-2191 is based on the chemotherapy drug methotrexate and has been formulated for injection into the eye.

The results come from just eight participants, all of whom had genetic mutations that caused faulty rhodopsin, a protein key to visual function. Aldeyra believes preclinical evidence points to methotrexate potentially helping facilitate the clearance of mutated rhodopsin. The trial took place over the relatively short period of three months, during which participants received regular injections once or twice a month.

Aldeyra reported no safety concerns, with injection site pain being mild or moderate. The company now intends to discuss a potentially pivotal Phase 2/3 trial with regulatory authorities in the USA. The next trial would collect enough data to more clearly demonstrate any beneficial effect.

A new gene therapy company

Retina UK grantee Professor Robert MacLaren has been central to the launch of a new ophthalmic gene therapy company, Beacon Therapeutics. The company aims to initiate clinical trials of a gene therapy, developed by Professor MacLaren, which targets cone-rod dystrophy caused by the CDHR1 gene.

Beacon Therapeutics has also acquired the X-linked RP and achromatopsia gene therapies previously pioneered by AGTC. These are further along the development pathway, with the X-linked RP therapy (for the RPGR gene) at phase 2/3 clinical trials, and the achromatopsia therapy at phase 1/2. These are not to be confused with the X-linked RP and achromatopsia gene therapies being trialled by the Janssen Pharmaceuticals – MeiraGTx partnership.

Boosting healthy gene activity

Australian company PYC Therapeutics is exploring a new approach to genetic therapy, by linking molecules called antisense oligonucleotides (AONs) to special protein-type structures that aid the AON's entry into cells. The AONs are precisely designed to place a molecular "patch" over certain strands of genetic code, either to cover over harmful code or manipulate the way

a gene is used. The technology could eventually be applied to various types of disease.

PYC Therapeutics has now started its first clinical trial, testing a therapy for autosomal dominant RP caused by a faulty PRPF31 gene (also known as RP11). In this type of RP, retinal cells are able to produce some healthy PRPF31 protein, but not enough of it to exert the required effect. The AON used in this therapy dampens the activity of a particular genetic "off-switch", thereby boosting production of healthy PRPF31 and supporting retinal cell survival. So far, only a few people have received the therapy, with the main aim of the current trial being to establish safety.

Enhancing stress resilience

Working at an earlier stage of therapy development, researchers at the University of California have discovered a new class of drug that could play a role in slowing retinal degeneration, particularly in its earliest stages. Described as stress resilience-enhancing drugs, or SREDs, these molecules can potentially boost the retina's ability to withstand the damaging knock-on effects of any faulty gene, preserving function for longer. It will be a while before SREDs can be tested in people, but this kind of approach could one day be used either on its own or in tandem with other treatments such as gene therapy.

ProQR – Théa agreement fails

The planned handover of ProQR's potential therapies for Usher syndrome and Leber congenital amaurosis to Laboratoires Théa will unfortunately no longer go ahead. The agreement was reliant on a number of ProQR staff moving over to Théa, and some of these individuals have decided against making the move. This means that the continued development of the two treatments is uncertain, although ProQR will remain on the lookout for alternative partnership opportunities. For more information, see the news section of our website.

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

Join the Retina UK Lived Experience Panel to hear about opportunities to take part in research-related activities. Visit **RetinaUK.org.uk/lived-experience** or call our office on 01280 821334.

Festive fundraising

Whether you're dashing through the snow or cosying up next to a warm fire, this Christmas there's plenty of ways you can support us.

Cards crafted exclusively for Retina UK by the artist Tina Wray

Each pack contains six cards, measuring 21 x 15 cm, with envelopes. Inside, it reads 'Seasons Greetings.'

Christmas cards

This holiday season, add a touch of magic to your festive traditions with our stunning Christmas cards. These exquisite cards depict a winter wonderland, with snow-capped buildings surrounding a magnificent Christmas tree, a picturesque snow-covered church, and an enchanting icy river flanked by snow-covered banks. Crafted exclusively for Retina UK by the incredibly talented artist Tina Wray, who, despite having retinitis pigmentosa and glaucoma, with less than 5% of her vision remaining, has brilliantly captured the essence of the season. By choosing these cards, you'll not only spread holiday cheer but also contribute to raising awareness and much-needed funds.

Each pack contains six cards, measuring 21 x 15 cm, with envelopes. Inside, it reads 'Seasons Greetings.'

All production costs have been generously donated by Penbow Displays Ltd and Fast2Finish. With your purchase, you're not only sharing the joy of the season but also directly supporting people affected by inherited sight loss.

To purchase a pack, priced at £3, please visit: **RetinaUK.org.uk/shop**.

Our Christmas cards are now on offer. Buy two packs and get one free with code **XMAS23**.

Stamps

As you receive cards this festive season, keep the stamps for our appeal. If possible, cut them out, leaving 5-10 mm of envelope and post them to us. Simply write 'FREEPOST Retina UK' on the package (please only use FREEPOST once you have approximately 200g of stamps - this helps keep the appeal costs as low as possible).

If you have a smaller quantity of stamps and would like to send them, please pop them in a stamped envelope to Retina UK, Whiteleaf Business Centre, 11 Little Balmer, Buckingham, MK18 1TF. Why not ask your friends and neighbours to collect stamps too!

Nurturing young scientists

As part of our aim to nurture young scientists, we are very pleased to introduce one of our new PhD students as part of a co-funding agreement with the Macular Society.

Chloe Brotherton is studying at Edinburgh University under the supervision of Dr Roly Megaw. She is working on a project that aims to increase the understanding of why different mutations in the RPGR gene impact photoreceptors in different ways, either leading to retinitis pigmentosa or cone-rod dystrophy. She talks about her background, why she took on this studentship and her hopes for the future.

"I completed my undergraduate degree in genetics at the University of Glasgow, then went onto a Master's in Medical Genetics and Genomics, also in Glasgow. I knew that I wanted to work in research related to genetic disease, and I've always been passionate about using my skills to help people. I could never be a doctor - too much blood and gore - so I started looking into studentships and I found this one in Edinburgh. It's something I feel passionate about, could put my energy into, and could get a lot out of at the same time."

"I became passionate about sight loss when I realised how life altering it can be. My partner's father has retinoschisis, a condition that causes a cleft in the retina. He told me how he went from driving a car when he was 18 to not being able to see much at all. I wanted to go into research and help people at the same time, and this seemed like a great place to start."

"I'm looking forward to so much about this project. I love learning more about science, but I'd also love to talk to people affected by inherited sight loss, to really learn the impact it has on their lives, and develop my skills and knowledge in order to help more people in the future.

“Going from a very structured environment to one where I have to make my own routine is a steep learning curve, but I love getting to talk to scientists about science. I genuinely think that there’s no one more passionate in the world than a scientist talking about their research. They get so excited, and to have that every day, to be a part of that, feels really good. The University holds seminars every Tuesday where I’ll get the chance to learn about what other people are researching.”

“I hope to continue studying in academia and research, increasing my lab skills, knowledge and communication skills to get through to people all over the world. All these things will add to my academic career. One of my long term goals is to publish a paper one day on my research, and perhaps lead a project down the line.”

Some readers may remember Elena Piotter, who started her PhD in 2020; a project also co-funded by Retina UK and the Macular Society. She describes her experience working on a project at Oxford University investigating the efficacy and safety of potential gene editing approaches for the treatment of Stargardt disease.

“The project has been super exciting and not at all as I anticipated! I met and worked with some amazing people.

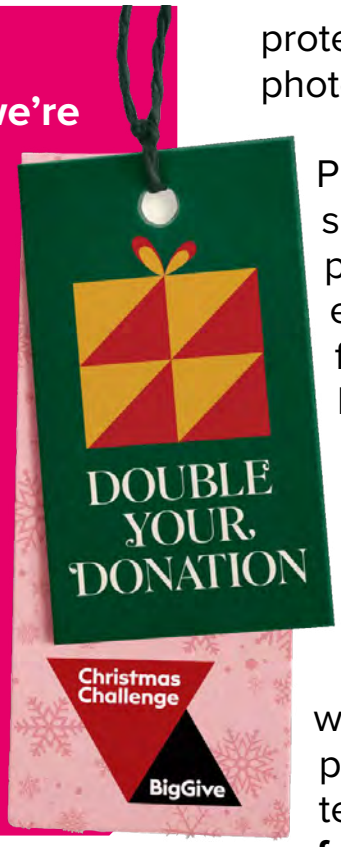
“It has had its ups-and-downs, but so far, we’ve shown that mutations in ABCA4 can be corrected by DNA and RNA editing. We have also found that it is very mutation dependent. In some cases, one or both editing systems work really well. In other instances, neither will work. We are currently trying a different kind of editing to circumvent this. The next step will be looking at testing this new method in retinal organoids, which I’m very excited about!

“I always loved science and wanted to pursue a career in this area, but didn’t know exactly what or how. When I started IRD gene therapy research pre-PhD, I didn’t know anything about eyes or CRISPR, but quickly came to love it. The PhD has allowed me to pursue this for longer and in more detail!

“I am really looking forward to what the future holds. I’m not quite sure what I’ll be doing next but in the short term I have extended the project until the summer to finish gathering data! I’m looking forward to seeing the final result and will update Retina UK after that.”

Double your donation with The Big Give 2023

The Big Give Christmas Challenge is back! And we're aiming to raise more than ever before. Our target this year is a staggering £45,000! Since 2017, through The Big Give, you have helped us raise more than £200,000 to invest in research into inherited sight loss. What an amazing achievement – thank you so much for each and every donation!



Between **midday on 28 November** and **midday on 5 December** your donation will be doubled*, at no additional cost, when you donate via the Big Give Christmas Challenge website.

- A donation of £12.50 will be doubled to £25, which could pay for two calls to our Helpline, supporting callers who feel isolated and alone.
- A donation of £50 will be doubled to £100, which could pay for four hours of medical research into potential treatments for people with inherited sight loss.
- A donation of £100 will be doubled to £200, which could buy an antibody needed for crucial experiments to see how RP mutations affect protein levels within light sensing photoreceptors.

Please make a note in your diary, set a prompt on your phone, or pop the card enclosed with this edition of Look Forward on your fridge. Visit **RetinaUK.org.uk/BigGive** between midday on 28 November and midday on 5 December for your opportunity to make twice the impact on inherited sight loss research.

If you have any questions or would like further information, please call our Fundraising team on 01280 815900, or email **fundraising@RetinaUK.org.uk**. Alternatively, please visit **RetinaUK.org.uk/BigGive** to find out more.

Thank you for your support – with your help we can raise an incredible amount for research into treatments for inherited sight loss.

**whilst the match funding pot lasts.*

The difference we made in 2022

Thank you to everyone who generously supported our work in 2022. Together we are able to make a real difference to the lives of people living with inherited sight loss conditions.

£1,562,632
Total funds raised

£624,853
Invested in medical research

£615,141
Spent on information and support

We are in touch with **8,300** people affected by inherited sight loss

902 new people began accessing our information and support

575 people registered for our local peer support group meetings

1090 Helpline calls and emails responded to

50,752 copies of *Look Forward* shared

6,148 online support group members

"It was so rewarding; meeting people in person, chatting and engaging on a personal level, swapping stories and real life changes that are needed."

"The telephone befriending service is brilliant. It makes such a difference being able to chat to someone who understands what it's like, I've never had that before."

"The first chance I ever got to meet someone like me was at a local group meeting These people just 'got' me in a way no one else had and I felt so accepted. It was a massive confidence boost at a time when I really needed it."

"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. 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."

"We met lovely people, and the staff made me feel very at ease and welcome. The Speakers and Researchers were amazing, caring and so passionate about helping others."

Follow the yellow brick road for a fantastic evenir

In August, London Peer Support Group facilitator, Bhavini Makwana, and fellow group members visited the iconic London Palladium to enjoy a touch tour and audio described performance of The Wizard of Oz.

Bhavini said: “Going to the theatre was high on the list of activities the group had suggested and The Wizard of Oz was a popular choice.

“The touch tour allowed us to meet cast members, feel some of the props and costumes, and learn where in the show they were used and by whom. This prior knowledge made listening to the audio description (via the head set provided) even more fascinating and really enhanced our experience. The show was magnificent, staff were on hand to support anyone who needed it, and all cast members portrayed their character brilliantly. You don’t need to have seen the film, but if you have, the songs will get you singing your heart out! I would definitely recommend the show to anyone.”

Group members Gill and Joan said:

“Well done to Bhavini and Retina UK for organising a fun evening. The Palladium and audio description staff were helpful and we enjoyed a touch

Does your workplace offer match funding or Charity of the Year partnerships? If so, we’d love to hear from you. Call us on 01280 815900 or email **fundraising@RetinaUK.org.uk**.

Fancy taking on the Brighton Marathon on 7 April 2024 for Retina UK? We have places available to take on this seaside marathon: **RetinaUK.org.uk/event/brighton-marathon/**.

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"You don't need to have seen the film, but if you have, the songs will get you singing your heart out!"

tour of various props used in the show. What a great start to future events!"

"I attended The Wizard of Oz with my daughter and we had a truly wonderful time! We met others in the group so conversations were flowing! Lovely to see guide dogs there too. It was such a beautiful evening - when is the next one?"

If you would like to learn more about our Peer Support Groups or have any ideas or suggestions for in-person group activities then please contact Mark Baxter at **services@RetinaUK.org.uk** or visit **RetinaUK.org.uk/groups**.

Could your local church choose Retina UK to be their charity partner for upcoming events or collections? Call us on 01280 815900 or email **fundraising@RetinaUK.org.uk**.

Next summer, why not take on the ASICS London 10K on 14 July in aid of Retina UK: **RetinaUK.org.uk/asics**.

One of our supporters, Celia Dawson, recently embarked on a sailing adventure with Sailing Vision Trust **(sailingvision.org)**. They aim to help visually impaired people experience the freedom and empowerment of water sports - especially coastal sailing.

Celia wrote: "There were 20 yachts taking part with very experienced skippers and sighted crew, along with two visually impaired travellers on each boat. Starting at Falmouth, we sailed along the south coast visiting Fowey, Plymouth and many lovely coastal villages.

"We experienced all the tasks involved in sailing, including pulling ropes, putting up the sails and being at the helm. It was a joyful and invigorating experience with so much laughter and teamwork. We made new friends and caught up with old ones, some of whom were also visually impaired.

"Having taken part for three years running now, the week gave me confidence to have a go and I hope to go again. I recommend this to anyone even if you have never sailed before."

Spotlight on Dr Katerina Tavoulari

Katerina joined the Retina UK team at the start of 2023 after hearing about the charity through her involvement in a research project at the University of Bath, where she works as an academic.

She said “given my professional academic background in disability, with an emphasis on visual impairment,” she was “naturally drawn to the work of the charity”.

After collaborating with some of the team she “was really impressed by the organisation, mission and the supportive community they had built” and let us know she’d be interested in volunteering with us... Naturally we jumped at the chance!

Now, nine months later, Katerina is the Local Peer Support Group Facilitator for Bristol, Bath and Wilts and is finding the experience extremely rewarding. She said: “Even though I don’t have a visual impairment myself, I feel immensely supported by the team, by fellow volunteers and by individuals with a visual impairment who have generously assisted me with practical matters. My first experience at the Retina UK Annual Conference in London with all these people was amazing, because I felt like they embraced me.”

We love volunteers and if you’d like to support our work like Katerina, please get in touch and we’ll jump at that chance too! Call Verity on 01280 821334 or email **volunteering@RetinaUK.org.uk**.

To find out more about our Local Peer Support Groups, including Bristol, Bath and Wilts, visit RetinaUK.org.uk/groups or email **services@RetinaUK.org.uk**.

Spotlight on Daniel Summers

Dan found out he had retinitis pigmentosa in February last year, but he feels it has been "on cards for years". He said he had "an inkling something was up but never did anything about it: a typical guy I guess!"

"It's been nice to DO something, rather than sitting and dwelling on it".

*Dan was treated privately, rather than on the NHS.

His grandparents pushed him towards seeking medical advice and, within the space of two or three weeks he had a diagnosis*. "That was obviously a lot to take on", he said, and he found himself wanting to "DO something". He mentioned this to one of his clinicians, and they recommended he contact Retina UK about volunteering.

Getting straight into the thick of it, Dan went to our annual volunteer training weekend and met people with the same genetic diagnosis as him, which he found really useful. He's now one of our Technical Support Volunteers which means he's able to use the skills he has from working in IT, for his volunteering.

Dan says his vision is still "pretty good", and he's appreciating being able to use that vision to help others with inherited sight loss conditions with things they now find difficult. In typically laid-back style, he says it's been "nice to DO something, rather than sitting and dwelling on it".

If you'd like to "DO something", call Verity on 01280 821334 or email **volunteering@RetinaUK.org.uk**.

Find out more about Genetic Counselling and Genetic Testing on our Unlock Genetics site: **RetinaUK.org.uk/genetics**.

Support us to help more people on their sight loss journey.

Make a donation online between 28 November – 5 December and it will be doubled* at no extra cost to you as part of The Big Give Christmas Challenge. Find out more on page 17.

*whilst the match funding pot lasts.

Complete this form and return to Freepost RetinaUK.
Or donate online at RetinaUK.org.uk/donate
Call 01280 815900 or scan this QR code:

☐ I enclose a cheque for £_____ payable to Retina UK

☐ I would like to donate £_____ by debit/credit card

£25 could pay for two calls to our Helpline, supporting callers who feel isolated and alone.

£50 could pay for two hours of medical research into potential treatments for people with inherited sight loss.

£95 could pay for one PhD student for a day.

Debit/Credit card details

Account holder name:

Card number: | | | | | | | | | | | | | | | |

Expiry date: | | / | | CV number: | | |

Contact details

Title: Name:

Address:

Postcode: Telephone:

Email: ☐ Tick here to be contacted via email

We love being able to update you with what we're up to and we will continue to contact you in the same way we always have. To change your preferences please call 01280 821334.

Gift aid your donation and give an extra 25p for every £1 you donate, at no extra cost to you!

☐ Yes, I'd like to gift aid my donation.

☐ I confirm that I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Signature: Date: