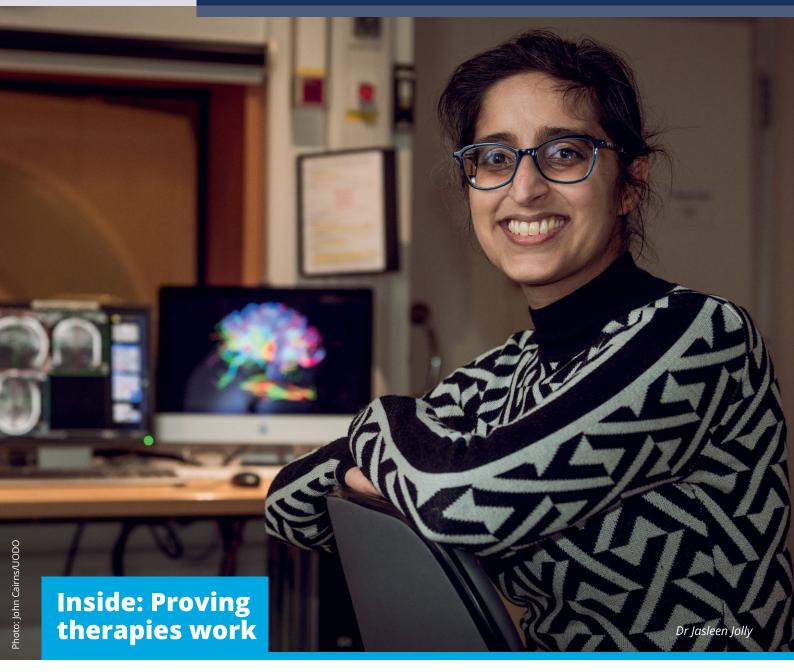


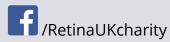
# LOOK Forward

ISSUE 179 SPRING 2023

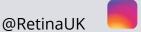


Inside this edition, read how a £250,000 Retina UK-funded project will begin developing an 'off-the-shelf' stem cell treatment that could benefit a large proportion of retinitis pigmentosa (RP) cases. Also, how studies focusing on the everyday experiences of those with inherited sight loss can be as important as clinical trials in changing the future.

Plus all the latest news including our 2023 conferences, webinars and local groups.







### **Renewed energy**

Finally, the first signs of spring and the lighter evenings we all look forward to are upon us, bringing a renewed energy for the year ahead.

The Retina UK team is busy planning our conferences (page 3) and I hope many of you will choose to join us in London this year as we love getting together in person.

Many of our growing number of local peer support groups around the UK are also back in the swing of meeting face to face, enjoying each others' friendship and support (pages 10-11). You can find your local meeting on our website RetinaUK.org.uk/groups.

As Retina UK is entirely funded through voluntary donations, we simply couldn't maintain our information and support services, or our medical research, without your generosity.

A heartfelt thank you to everyone who contributed to our appeal last year, we raised over £64,300! What an amazing sum for us to put towards

finding treatments for all. And also to those who took part in our annual raffle, we're glad so many of you took up playing online, helping us raise over £13,600.

There are many fun or challenging ways for you to help us raise much-needed funds. If you would like to set yourself a challenge for 2023 there are some great ideas on pages 20-21 - some you can do from your own doorstep.

There has been some sad news too with the passing of key members our community including Norman Pampel, a former trustee and treasurer of our charity for many years. We remember Norman's valued contribution and send our condolences to his family and all those who have lost loved ones.



Tina Garvey **Chief Executive** 

We have a new look privacy policy that includes a separate cookie policy, you will find both on our website at RetinaUK.org.uk/privacy-policy. Please do contact the office if you have any questions.

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. Retina UK, Wharf House, Stratford Road, Buckingham MK18 1TD E: info@RetinaUK.org.uk · T: 01280 821334 (Office) · T: 0300 111 4000 (Helpline) W: RetinaUK.org.uk · E: helpline@RetinaUK.org.uk

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

Yohnson-Johnson

#### **INFORMATION AND SUPPORT**

### Join us at our Conferences and AGM



We are delighted to tell you about our Annual Conference on Saturday 24 June. We are hosting the conference at the University of Westminster Marylebone Campus in London as well as online.

We have a packed day planned with speakers exploring areas including future technologies, how Retina UK is getting your voices heard and medical research. A great line up of eminent medical professionals will join us to answer your questions on all things inherited sight loss.

This conference is free to attend. Registration is now open – visit **RetinaUK.org.uk/annual-conference** or speak with our friendly team on 01280 821334.

#### Our CPD-accredited Professionals' Conference is back!

We have a specific focus on how we work more closely with professionals this year, and we would like to welcome professionals to our CPD-accredited conference on Friday 23 June. We are hosting the conference at the University of Westminster Marylebone Campus in London as well as online.

This conference is free to attend. At this information-packed day, we'll discuss how we can help you to best support your clients with inherited sight loss, share patients' experiences of the sight loss pathway and update you on the latest research into inherited sight loss.

Registration is now open at **RetinaUK.org.uk/prof-conf**.

#### RESEARCH

### New project has potential for far-reaching impact

Our most recently awarded research grant will fund efforts to begin developing an "offthe-shelf" stem cell treatment that could be of benefit in a large proportion of retinitis pigmentosa (RP) cases, regardless of the underlying genetic fault.



Prof Linda Lako at Newcastle University will lead a three-year £250,000 project to test the feasibility of creating stem cells that can evade the body's natural immune responses, allowing them to be transplanted into anyone's eye with a greatly reduced risk of immune rejection. The aim of the therapy would be to replace lightsensing photoreceptors that have degenerated due to RP, an approach that does not rely on a targeting any particular gene.

Pluripotent cells are a type of stem cell that can potentially be coaxed into developing into any of the body's specialised cells, including photoreceptors. Prof Lako and others have shown that photoreceptors generated in this way can branch out to make links with nerve cells, suggesting that they might successfully integrate into the retina after transplant.

Pluripotent cells are found in early embryos and can also be generated from adult skin and blood cells, but transformation to photoreceptors takes considerable time, and the resulting cells carry markers that are unique to the original donor, meaning that another individual's immune system would see them as "foreign" and mount an attack to remove them. Studies in mice have indicated that transplanted photoreceptors derived from stem cells are lost within a few months, most likely due to the host's immune response. These issues present considerable challenges for timely and effective treatment.

Prof Lako and her colleagues will explore an innovative approach to getting round this problem by genetically modifying pluripotent stem cells to render them "invisible" to a recipient's immune system. The team will then encourage the cells to develop into photoreceptors, before mixing them with immune system cells to see how they interact – the modifications to the photoreceptors should mean that the immune cells are not provoked into attacking them.

During the final part of the project, the researchers will transplant the cells into the retinas of mice with a genetic fault that causes degeneration similar to that seen in the later stages of RP in humans. The team will evaluate the ability of the transplanted cells to make connections with the mouse retinal nerve cells, and will also examine the immune response in the mice. However, the ultimate test for assessing whether or not the cells hold real promise as a treatment will be to examine their ability to restore vision in mice with advanced retinal degeneration. This will involve a range of behavioural and physiological tests.

Ultimately, Prof Lako hopes to establish the feasibility of this treatment as a readily accessible and sustainable approach for restoring some degree of vision. She told us: "This project is the first step of a journey towards clinical application, and will provide essential proof of concept. We believe



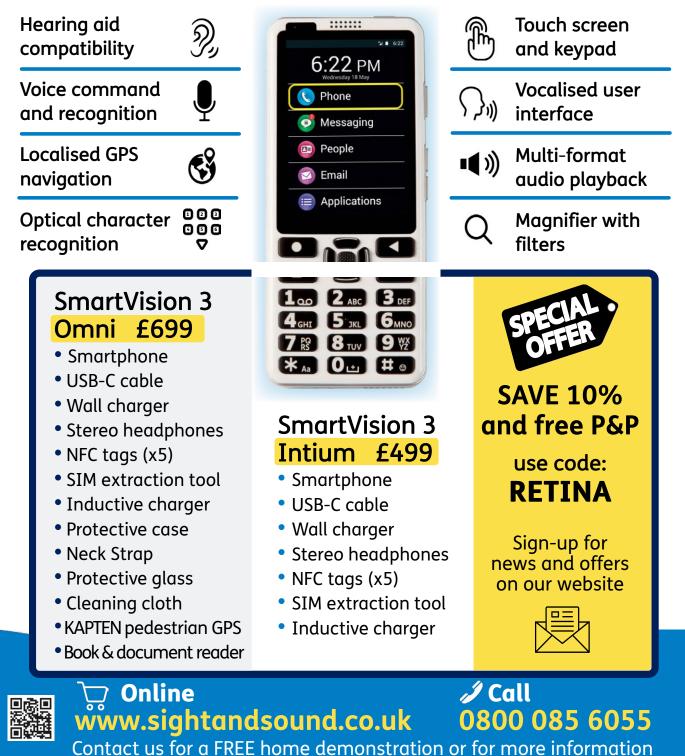
Prof Linda Lako

that our approach could have farreaching impact, potentially benefitting a significant proportion of those with retinitis pigmentosa."

Retina UK is very grateful to the AT Capital Charitable Foundation for fully funding this project, helping us to keep funding more researchers. The AT Capital Charitable Foundation is a Singapore registered private charity founded by Mr Arvind Tiku's family office and focused on healthcare and education worldwide. As the UK's leading provider of hardware and software solutions for the blind, visually impaired, and people with learning, reading, and writing difficulties, our products can improve your quality of life at work, at study or at home.



### **SmartVision 3 Mobile Phone**



#### FUNDRAISING

### Getting in the swing of fundraising



Securing support from companies could make a substantial impact on Retina UK research funding.

We know companies are much more likely to choose to support Retina UK with workplace fundraising, Charity of the Year partnerships, Gifts in Kind, or matched funding if a member of our community or a friend or family member recommends Retina UK.

Last year, Liam Weatherall, an employee at Coventry based TBL and LDM Scanning Limited nominated Retina UK as the company's Charity Partner for their annual Golf Day. It was a great success and TBL and LDM Scanning Limited generously donated £1,200 to Retina UK. The company has continued to support us and has chosen Retina UK as its Charity Partner for the Golf Day again this year.

#### We need your help

Do you, or a friend/family member work for a company who support charities? If so, please get in touch with Fiona Leahy, our Corporate and Community Fundraising Officer on 07736 958207, or email **fiona.leahy@RetinaUK.org.uk**.

#### VOLUNTEERING

### "Retina UK is all about people"



The mum-of-three from Essex takes calls on our helpline for one shift a week, fitting her volunteering around looking after her family, her job as a social worker and studying at university.

Cindy experienced problems with her sight as a child and was labelled as 'clumsy'. She didn't receive any specialist support or fully understand the impact of her retinitis pigmentosa (RP) until she was at university and referred to Moorfields Eye Hospital. Cindy comes from a large family but there was no history of RP.

"At the time I didn't know anyone with a visual impairment or disability," she said. Cindy lost her sight when her youngest son was aged one. She had been told her boys wouldn't be affected by the condition but this wasn't to be the case.

"When I was reading Biology at university I did a module in genetics so I asked about inheritance. I was told because there was no family history, there's no way it was dominant, and my children wouldn't be affected unless my husband has the same gene," she said.

"When two of my children were aged six and 11 we found out they both have it. I only got my genetic diagnosis after my boys were diagnosed. We all had the same gene responsible for dominant RP."

VORKING

### So what led Cindy to Retina UK and volunteering?

"I first came in contact with Retina UK in 2000 after being told about the charity by Moorfields Eye Hospital. My first experience was attending an annual conference.

"I wanted to volunteer due to my own experience of RP. I had dealt with my sight loss, and my sons' sight loss, and come through the other side, and I wanted to help someone else with that. Volunteering can fit around what you've got on, it's flexible, interesting and you get to meet other people."

Cindy is currently training to teach

social workers and describes her life as 'very chaotic', but says her work and volunteering activities complement each other and she likes to be busy. "When I wanted to apply to be a social worker, volunteering helped as skills developed through volunteering supported the application.

"The training I've received at work benefits my volunteering role, such as knowing about the support services available. My life experience helps with my volunteering and work. It all plaits together."

Cindy says her role on the helpline can be emotionally challenging and that she values Retina UK training weekends.

"You need to be realistic. You are volunteering, but it can be emotionally heavy so you need to be resilient.

"The training weekends are very helpful, they enable you to get a greater understanding of the research side of things and also listen to other people and their experiences."

As for what she gets out of volunteering, Cindy said: "It's rewarding in so many different ways. You are part of something and talk to people who are on same wavelength, who understand. Retina UK is all about people."

If you are interested in becoming a Retina UK Volunteer we would love to hear from you. Please email Clair on **volunteering@ RetinaUK.org.uk** or call our office on 01280 821334.

TOW PEOPLE WITH INHERITED SIGHT LOSS

#### INFORMATION AND SUPPORT

### Friendship and support



As we head in to 2023 our Local Peer Support Groups are going from strength to strength with many in-person meet ups and events, which have been positively received.

#### Berkshire

Berkshire Local Peer Support Group met in December at a restaurant. Group facilitator James said: "It was lovely to catch up with newly made friends over a festive lunch."

#### Belfast

Group facilitator Kim met the group in-person in January over a coffee and a talk about Discovering Art at the Ulster Museum in Belfast. Kim said:

Berkshire Local Peer Support Group

"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 art lecture was fascinating as I would never have known such depth could be in a painting as I often miss things due to vision – hugely recommended."

#### Manchester

The group joined volunteer facilitator, Rachael, for a social catch up over a drink and bite to eat. She said: "It is great that we have new people joining us and the group is always growing."

For details of forthcoming meetings across the UK visit **RetinaUK.org.uk/groups**.



Belfast Local Peer Support Group

#### **Our latest webinars**

### Low vision services, aids and equipment

**Thursday 23 March 7.00pm-8.00pm** Join us and the Low Vision Team from Focus Birmingham to learn about how you can access your local low vision service, the benefits of a low vision assessment and some of the equipment that can be provided.

#### Getting involved with Retina UK, the value of volunteering Thursday 13 April 7.00pm-8.00pm Explore the value of volunteering with the Retina UK team. Our

speakers will tell us about the many positive impacts volunteering has had for them, from raising their selfesteem and confidence, to securing employment.

#### Hair care and styling

**Thursday 18 May 7.00pm-8.00pm** Hair Stylist Anna Cofone will explore all things hair and scalp care. A session hairstylist with 20 years' experience working in the fashion and music industry, Anna will talk about how to determine the texture and type of hair and what products to use.

All our webinars are free to attend, register at RetinaUK.org.uk/webinars.

### Dream big, anything is possible

We regularly work with sector partners where their work complements ours and they share our values. VICTA is a national charity that provides support to children and young adults who are blind or partially sighted and their families. **VICTA** believes that everyone has the right to an independent and fulfilling life. In the following article they describe their work.



Research shows that cooperative learning improves a student's achievements, persistence, and attitudes. Collaboration with fellow learners increases motivation and helps students take responsibility for their own and their peers' learning. In turn, we witness how collaboration leads to the development of life skills such as increased confidence, selfadvocacy, empathy, problem-solving and social skills.

Lucy Ashton started her VICTA journey when she was 16 years old. "I was shy and nervous about going on an overseas trip with 12 other people I didn't know. I can now say that the trip to Romania with VICTA changed my life. With the support from the VICTA volunteers and my peers, I learnt so much about myself and my vision impairment.

"Throughout school I really struggled and felt as though I never accepted my vision impairment as it became a hassle for others, and I didn't receive half the support and understanding I got from VICTA. My first VICTA trip made me realise that it's ok to have a vision impairment and it's a part of who I am. From then on, I have participated in several activities and have met some incredible people and made friends for life. I have had some 'once in a lifetime experiences' and I cannot thank VICTA enough for what they do and have done for me."





Our Young Achievers Award (0-9) is designed to encourage learning through participation not instruction while our Pre-Teen Activities (10-13) support the transition into secondary education with a programme that builds confidence, self-belief and self-advocacy. Youth Activities (14-17) including an Expeditions Programme (Duke of Edinburgh Award & John Muir Awards) support personal growth and the transition into higher education. Our Young Adult Activities (18-29) are designed to support the development of life skills, wellbeing and the transition into adulthood and the workplace.

To support this, we developed a number of online resources. The VICTA Student Portal (10-29) is a one stop information hub designed to help VI students manage their emotional wellbeing and take control of their educational and employment experiences. While the VICTA Parent Portal and Parent Network both signpost and connect parents to information and advice helping them to navigate life with a child with sight loss. We want everyone to be motivated



to reach their potential. One VICTA student captures our ethos perfectly: "We have to push ourselves out of our comfort zone to try new things, we just have to find new ways of working around our disability. Dream big. Anything is possible."

Find out more at: victa.org.uk victastudents.org.uk victaparents.org.uk admin@victa.org.uk @VICTAUK

While Retina UK does not provide direct support to under 18s, all of our information and support services are available to parents and the wider family.







John ran the Bath Half Marathon, completing the race and raising a brilliant £675.



A big thank you to Robert Preece, and all the members of Freemasons, Lodge of Sincerity, in Bristol for their £1,000 wonderful donation in October 2022.



Katie and Andrew took' on the Great Scottish Run 10K, raising an amazing £715.



Kirsten and Tom took to the sky and skydived from 15,000ft for Retina UK! Between them they raised £915 – thank you.

Natalie, Sarah and Lorraine ran the Loch Ness Marathon together and raised an incredible £1,474.





Gwyneth, Samantha and Jade joined the Retina UK Great Bake, rustling up some tasty treats for the local community and raising £255.

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

Many talented performers gave their all, famous faces volunteered their time and awareness of inherited sight loss was raised as hundreds of people packed into the North Notts Arena for Worksop's Got Talent. We want to say a huge thank you to the mastermind of the show James Clarke who has now raised over £100,000 for Retina UK.





Graeme Stewart began running at the end of last year and has gone on to complete the Glasgow 10K Winter Warmer Run and raise £300 – amazing!

Flo Barker crocheted beautifully handcrafted baubles and raffled them, raising £425.



A huge thank you to our Oxford Local Peer Support Group for organising a bucket collection at Asda in Wheatley, raising £272 in support of Retina UK.



Katy Newitt sailed over 2,500 miles, from Dubai to Egypt, to help inspire others living with inherited sight loss. An incredible journey, which has raised £4,863 to date in aid of Retina UK.

A big thank you to Josie Grist, and colleagues at Costello Medical, for holding a Valentine's Day Bake Sale at their London and Cambridge offices raising £175. This follows a Souper Tuesday workplace lunch which raised £293.

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

### **Researcher profile: Dr Jasleen Jolly**

It's exciting to read about potential treatments progressing through the clinical testing process. But studies focusing on the everyday experiences of those living with sight loss can be just as important as clinical trials in changing the future.

Before any treatments can be made widely available, they need to clear a series of hurdles with medicines regulators and the NHS by demonstrating they make a significant difference to day-to-day life. This requires meaningful measurement of the impact of the condition, as well as of the therapy.

"Unless you can prove a therapy works, it will never be brought into patient care. The process of impact measurement is as important as development of the therapy but not paid the same attention" says Dr Jasleen Jolly, Associate Professor at the Vision and Eye Research Institute at Anglia Ruskin University.

Dr Jolly is an expert in genetic eye disease and low vision, whose work combines optometry, ophthalmology, neuroscience and psychology.

"I grew up in a medical household and trained as an optometrist as I am passionate about quality of life – I felt that optometry allowed me to focus on this more than medicine" she told us. "I was always interested in research and incorporated it into my clinical practice at every stage of my career. My master's degree included ocular genetics research, and that led to me working at Oxford on gene therapy clinical trials for inherited retinal conditions."

Dr Jolly quickly realised the need for clinical trial results to reflect how the treatment was impacting on participants' real world, everyday experiences. She now dedicates much of her work to the investigation of better outcome measures for trials.

"There is a history of clinical trials failing due to the use of the wrong outcome measures across medicine, and ophthalmology is no different" Dr Jolly explained. "The traditional tests people regularly undertake at their ophthalmology check-ups are designed for screening or diagnosis. They are not designed to pick up the changes we are looking for in the new therapies, and often fail to do so, with some areas of medicine showing a 50% rate of failure of clinical trials.

"The regulatory authorities want to see that a new treatment is making a real difference to quality of life, but finding a balance between a clinical test and reflecting someone's real world experience can be quite difficult. That is why we need dedicated research to explore how to do this."



Dr Jasleen Jolly

This type of research relies heavily on the willing participation of those living with the conditions concerned. However the benefits of taking part in some types of research are perhaps not so clear. If you complete a survey for a researcher, how is that really helping?

Dr Jolly gives an example based on a study recently published by her team, this time around the impact of diagnosis: "We gathered questionnaire and interview data about the psychological impact of receiving a diagnosis that involves sight loss. As the Retina UK community will know, many who receive such diagnoses feel as if they have been 'hit by a brick'. We did a study to understand how to best help patients through this difficult moment and the long-term effects. "We have used the outcomes of the study to educate clinicians on their communication. Among the recommendations we made is that it helps a lot when clinicians connect patients with information, community, and support groups such as charities as early as possible in the process. This is just one example of how hearing a person's take on their own lived experience can help us determine needs and shape healthcare outcomes to better serve everyone affected by these conditions."

Dr Jolly and her colleagues are conducting studies on various aspects of life with sight loss. Register your interest at aru.ac.uk/vision-and-eyeresearch-institute/get-involved. She is currently recruiting for studies on the visual hallucinations that some experience as a result of sight loss (Charles Bonnet Syndrome). Travel expenses will be reimbursed.

One study in Oxford needs people both with AND without hallucinations to go into an MRI scanner. Contact **brain@ eye.ox.ac.uk** for information. The other, in Cambridge, is asking people with frequent hallucinations to undergo an EEG. Contact **Bethany.higgins@aru. ac.uk** for more information.

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

#### PARTNERSHIPS

### Stronger together – collaboration is key



We regularly involve other organisations in our research, information and support, and awareness-raising activities because we know we are stronger when we work well together.

Paula McGrath, Retina UK Deputy Chief Executive, said: "The Retina UK team collaborate daily with a wide range of organisations who want to improve the lives of those living with inherited sight loss, and share our values. Quite simply, we know we make a bigger difference when we work well together and we value everyone's contribution."

#### Research

Potential treatments must meet the needs of those living with sight loss

and make a meaningful impact on day-to-day life. Biotechnology and pharmaceutical companies are actively seeking to understand the experiences of people with inherited sight loss conditions so they can make real progress, and that's where Retina UK comes in.

We often put companies in touch with willing members of our community to talk about their experiences, via focus groups, interviews or patient committee meetings. For example, we helped ProQR Therapeutics recruit two people from the UK, living with a particular type of inherited sight loss, to join the company's international patient committee. This group helped the company introduce more accessible information and encouraged them to consider the wider impacts of life with sight loss.

Andy Bolan, Director of Corporate Affairs at ProQR Therapeutics, said: "The way health research and clinical trials have been developing in recent years, particularly in genetic medicine, means it is critically important for companies, like ours, to be guided by the very people who would be receiving the treatments. Our in-house Inherited Retinal Dystrophy (IRD) advisory committee, made up of individuals and supporters living with IRDs we were researching, met regularly online and provided us with such valuable insights. Retina UK was our first port of call for finding the people we needed."

We also collaborate to fund research projects into inherited sight loss like our three-year PhD studentship at Oxford University, a project co-funded by the Macular Society.

Under the supervision of Prof Robert MacLaren, researcher Elena Piotter is looking into a potential new method for treating Stargardt disease and other conditions where 'conventional' gene therapy may not be possible.

#### **Information and support**

We partner with other like-minded organisations and charities actively working with people living with a visual impairment and improving people's lives. We are a founding member of the VI Charity Sector Partnership, a collaboration of charities working towards similar goals including local sight loss organisations, RNIB, Guide Dogs, Macular Society and Blind Veterans UK.

Through the partnership we are working to improve care and support by creating a Sight Loss Pathway. Our involvement, which has included consulting with members of our local peer support groups, means we can ensure the pathway is reflective of the unique experiences of those with inherited sight loss.

#### Awareness raising and influencing

By working together we can strengthen the voice of all those living with sight loss, including inherited conditions and get tangible outcomes sooner. We recently joined with over 25 other charities to urge the Government to put disabled people and those with sight loss at the heart of its response to the cost of living crisis.

Together we can reach a larger and more diverse audience to raise awareness of the impacts of sight loss. We can educate the public to enhance their understanding, which could lead to a change in attitudes and behaviour. This in turn would lead to a positive change for all.

We can make your voice heard so you can influence change. Join our lived experience panel **RetinaUK.org.uk/more-info**.

#### FUNDRAISING

### Join #TeamRetinaUK

Take on a challenge in 2023 and help provide support for today and accelerate the search for treatments for the future. Whether you want to walk, run or cycle, join #TeamRetinaUK.

#### **Edinburgh Marathon Festival**

27 – 28 May 5K – £10 fee / £100 fundraising 10K – £10 fee/ £175 fundraising Half marathon – £15 fee / £350 fundraising Full marathon – £15 fee / £750 fundraising

#### **Great North Run**

10 September – 13.1 mile run £15 fee / £350 fundraising

#### Lake District Challenge 10 – 11 June Peak District Challenge 8 – 9 July Jurassic Coast Challenge

#### 13 – 14 May

25, 50 and 100km challenge options available. Daylight only option also available for 100km challenge. Multiple fee options available – visit our website or call for details.

#### RideLondon-Essex 100

28 May – 100 mile cycle £5 fee / £500 fundraising

#### **Royal Parks Half Marathon**

8 October – 13.1 mile run £15 fee / £350 fundraising

#### Hopefully to Seaview

11 June – 5 mile walk in Ryde £10 fee

#### Take on a challenge in your neighbourhood

Join us on 23 April for the Virtual TCS London Marathon and get your very own marathon medal. Taking place on the same day as the mass event in London, you'll have 24 hours to complete your marathon. Whether you choose to take this on as a solo runner or find a friend to walk with, you can take part at your own pace and on your own route.

£5 fee / £145 fundraising

### How we support your fundraising

From running vests to cycling jerseys, our exclusive Strava running club to cheer banners, we'll be on hand to help with every mile. Last year, #TeamRetinaUK raised over £75,000! Could you join the team and help to raise even more in 2023? To find out about our full list of challenges visit **RetinaUK.org.uk/challenge** or call 01280 815900.



My Grandmother was diagnosed with retinitis pigmentosa 40 years ago, as well as my Dad's cousin within the last few years. I'm dedicated to raising money for this wonderful charity and supporting them in all the important work that they are doing. Running a marathon has always been a goal of mine and I feel very lucky to get the opportunity to be a part of the London Marathon this year. I'm looking forward to the atmosphere and seeing all the people who show up to take part and spectate.

Alex, who is running the TCS London Marathon this year



It's a truly extraordinary feeling to cycle through Parliament Square, up Whitehall and past Tower Bridge on the way out to Essex with absolutely no traffic on the roads. The Essex countryside is beautiful and it was extraordinary to find such enthusiastic vocal support all the way around the ride. My tandem partner Andrew and I were blown away by the fundraising support we received too. It never fails to surprise me how generous people are when they are faced with a good cause and someone taking on a challenge!

Martin, who cycled RideLondon-Essex 100 on a tandem with Andrew in 2022

### **Annual General Meeting notice**

ETINA

Our AGM will be held on Saturday 24 June at 4.00pm. You can choose to attend in-person at the University of Westminster, Marylebone Campus (directly opposite Madame Tussauds) in London or online.

Online, postal and telephone voting will be held in advance of the AGM, meaning all members who choose to do so can exercise their right to vote at a time, and in a format, that is accessible to them. All members with voting rights will receive information on how to vote.

We will present the results of the vote at our online interactive AGM meeting. All are welcome to attend the meeting where there will also be the opportunity to hear from our Chairman and Treasurer and to ask them, the Board and our Chief Executive questions. Register your interest in attending the AGM at **RetinaUK.org.uk/annualconference**.

#### Agenda

- 1. Welcome
- 2. Apologies
- 3. Approval of the minutes of the previous AGM (result of online voting)
- 4. Presentation of the annual report and accounts for the year ended 31 December 2022
- 5. Adoption of the Annual Report and Accounts for 2022 (result of online voting)
- 6. The appointment of the auditors (result of online voting)
- 7. Presentation of Retina UK activity in 2022 and 2023 overview – Chairman Martin Kirkup
- 8. The appointment of trustees (result of online voting)
- 9. Any other business.

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### **BlindShell Classic 2 - Mobile Phone - Free accessories**

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- No internet required for voice functions
- 13MP camera
   Up to 5 day battery life
- Includes all **standard smartphone features**: WhatsApp, YouTube, Facebook, email etc.

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- All in one **text-to-speech** and **6**" video magnifier
- World's first reading machine that accurately reads handwriting as well as printed text; books, post, greetings cards, newspapers, magazines, recipes etc.
- Automatic reading, place your document and it reads
- Shop with confidence with its instant barcode reader to easily identify your shopping
- Translates text between different languages
- Easy to use via tactile buttons and voice control

### **EYE5 - Wearable Magnifier - 10% Off with code RUK**

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## Make a lasting impact!

Your donations make a difference to those living with inherited sight loss. All funds raised go towards supporting our ground-breaking medical research, like that of Prof Linda Lako at Newcastle University, as well as maintaining our vital information and support services. Thank you for your help.

Complete this form and return to Freepost RetinaUK.

Or donate online at

RetinaUK.org.uk/donate	pay for a call to our Helpline!
I enclose a cheque for £ payable to Retina UK	<b>£40</b> could provide the use of a state of the art microscope for a week!
Debit/Credit card details Account holder name:	
Card number:   /     Expiry date:   /   CV number:	<b>£95</b> could go towards the funding
Contact details	of one of our researchers!
Title: Name: Address:	
Postcode: Telephone:	
Email: 🗌 Tick h	ere 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!

 $\Box$  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:





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

