

## Massive congratulations

to our London Marathon #TeamRetinaUK – see page 13



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# Weathering the storm

We hope that life is slowly getting back to normal. Like everyone, I'm definitely looking forward to seeing my friends and family at Christmas after the relative solitude of the 2020 festive period.

We may have weathered the storm of the past 18 months or so, but we know there are tough times ahead, not only for us but the whole charity sector. The cost of economic recovery is still uncertain; inflation is on the rise and government borrowing is stratospheric as a result of the support measures during lockdown.

The team here at Retina UK will continue to provide our information and support services and kick-start our funding of medical research into the causes of and treatments for inherited retinal dystrophies; but we can only do that with your help.

More than ever the wider community is relying on the charity sector for support, funding and services, and in turn we rely on our loyal and generous supporters. We need you now, more than ever!

Please do get in touch if you would like to take on one of our incredible challenge events or regularly support us (see pages 19 and 24).

The team was delighted to hear that our ambassador Steve Bate MBE secured a silver medal in the individual pursuit at the Tokyo Olympics. We are so proud of Steve and all of the other athletes who took part in the awe inspiring Olympic and Paralympic games.

This is the last *Look Forward* of the year so I would like to take this opportunity to thank our volunteers, trustees, supporters, community and staff for all of your help over the last year – we really couldn't do what we do without you. Rest assured that we will always face the future together as a team, and tackle whatever it may bring. Have a fantastic festive period and I look forward to continuing to strive for the best today and a better tomorrow in 2022.



*Tina Houlihan, 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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## Exciting developments for new treatment research

**In recent years there has, understandably, been a lot of excitement around cutting-edge therapies that target the specific genetic faults underlying inherited sight loss. After all, the only available disease-modifying treatment is a gene therapy: known as Luxturna, it works by providing retinal cells with healthy copies of the affected gene, in this case the RPE65 gene.**

However, this can only work for people whose sight loss is caused by faults in RPE65, and they probably number well under 100 in the UK. There are other such therapies in the clinical trials pipeline, for genes including RPGR (X-linked RP), USH2A (Usher syndrome type 2) and CNGB3 (achromatopsia), but inherited retinal conditions can be caused by faults in any one of around 300 genes. And of course we know that around 30% of our community do not get a result from a diagnostic genetic test, because the gene causing their sight loss is not yet identified or fully understood. What about the rest of our community? Do they need to wait for a therapy that targets their specific gene? Can they be treated successfully?

There is good reason to be hopeful. Research on one gene-specific therapy inevitably produces learning that is relevant to other genes,

helping accelerate progress. Several researchers and companies are looking at ways to enhance survival of retinal cells without targeting a specific gene.

### jCyte

For example, in spring 2021, the US company jCyte announced encouraging results from their successful phase 2b clinical trial of jCell, a stem cell-based treatment for RP that is not dependent on a particular genetic fault.

jCell is a proprietary preparation of retinal progenitor cells. These are stem cells that have only just started on the path towards developing into mature, fully differentiated retinal cells. The jCyte treatment involves injecting a dose of several million of these cells into the vitreous (jelly) of the eyeball, with a local anaesthetic.

jCyte do not expect their stem cells to integrate into the retina and replace degenerated photoreceptors. Instead, their rationale is that jCell will provide nourishment and support, by way of substances called trophic factors, to slow degeneration and improve survival in the remaining retina. It would therefore be expected that this approach would work best when there is still some relatively healthy retina left, and would not be successful if the retina was completely degenerated. This was borne out in the results of the trial; the best outcomes, in terms of reasonable improvement in visual

### Exciting developments for new treatment research *continued*

acuity, visual field, and low light vision, were seen in people with the greatest retinal thickness before treatment, as measured by OCT scans.

jCyte will now move forward to a larger phase 3 trial, which will recruit participants with a certain minimum retinal thickness, who have the best chance of responding well to the treatment. We will be keeping an eye out for a start date for this trial, although there may not be any UK trial centres. Once it gets going, the trial will probably take a couple of years.

#### ReNeuron

Another company, ReNeuron, is still at the phase 2 trial stage with a slightly different stem cell approach that involves injecting the cells underneath the retina under general anaesthetic. We hope to hear more from them in 2022 about whether this trial is successful.

#### Optogenetics

For those at a later stage of sight loss, an exciting technology called optogenetics holds promise. Some of you may remember seeing a BBC news story in spring 2021, about this type of treatment partially restoring the sight of a man living with retinitis pigmentosa in France ('Algae proteins partially restore man's sight', BBC News, 24 May 2021). The man, who had no remaining vision, first noticed improvement when he realised he could make out the painted stripes of a zebra crossing.



Optogenetics involves providing cells in the retina that don't normally sense light, but are unaffected by the disease process, with genetic instructions for building light sensitive proteins. These cells can then respond to light and send simple images to the brain. This could provide limited perception of objects, perhaps restoring some independent mobility to a person with severe sight loss.

At the moment, optogenetics is at a fairly early stage of clinical development for retinal degeneration; the news from France provided 'proof of principle' that

this particular optogenetics approach, developed by the company GenSight Biologics, could work in people with RP. GenSight Biologics has now initiated an early stage clinical trial. The treatment does require use of a pair of heavy, quite bulky 'goggles' to enhance light detection, which may need refining for day-to-day use. Other companies and research groups are also exploring different optogenetics strategies.

### **Inflammation and retinal degeneration**

Meanwhile, those of you who attended our September webinar (see pages 8-9) will have heard Dr Roly Megaw from the University of Edinburgh talking about his work on inflammation and retinal degeneration.

No matter what the causative gene in inherited retinal conditions, the affected retinal cells will ultimately degenerate. Roly is investigating the mechanisms underlying cell death to see if there is a common pathway that could be targeted. He has found that the degenerating cells trigger certain inflammatory processes, and there are drugs already in use for other inflammatory and neurodegenerative diseases that could potentially help slow deterioration of the retina. Roly pointed out that drugs could be used alongside gene therapies, and the most effective treatment regimes could eventually involve multiple approaches combined.

### **Research grant funding**

It's encouraging to know that researchers and industry are exploring so many avenues in the search for treatments. The grant applications that will be considered in our current research funding round include some projects investigating gene-independent therapeutic approaches, while others look at gene-specific strategies. We have only been able to consider these applications thanks to your generous ongoing support. You can find out more about opportunities to help us further on pages 11, and 24.

## **Our current research funding round**

# **12**

**Preliminary research grant applications**

# **6**

**Projects invited by our Medical Advisory Board (MAB) to submit full applications.**

**Applicants are requesting in the region of £200,000 – £250,000 for each project.**

**Decision spring 2022.**

# Talking about wellbeing

**We know that many people who live with or are affected by inherited sight loss experience anxiety, worry and uncertainty about the future.**

When we carried out our Sight Loss Survey in 2019 (see page 7), **92%** of respondents told us they experienced psychological effects, with the most common being **loss of confidence, anxiety and stress.**

Sadly the pandemic has made these existing feelings worse. Calls to our helpline have increased in both volume and length – with a **68% increase in calls** taken October to December 2020 versus the same period in 2019, and a **115% increase in the average call length.**

An important and growing area of our work is to enable all those we are in touch with to actively manage their day- to-day wellbeing – how comfortable, happy and healthy they are – by providing them with useful, practical tools.

In 2020 we worked with Arthur Ellis Mental Health Support to provide our volunteers with a series of online training modules to help them identify and deal with issues surrounding their own wellbeing. This was a vital part of enabling them to better support

our community, many of whom were facing challenges that our volunteers (all of whom are living with or affected by inherited sight loss) could often identify with. This training was well received:

*“Mental health and wellbeing has never been more important in these days of coping with Covid-19. In order to protect ourselves, our helpline team and our clients, we need the tools to recognise our individual and team boundaries.”*

*A helpline volunteer*

In 2022, thanks to sponsorship from Janssen and grant funding from Novartis, we will further develop this work with Arthur Ellis Mental Health Support to provide additional training for volunteers and to create accessible training resources for our community. These guided modules will empower people to explore and manage their own wellbeing at a time that suits them.

We look forward to sharing more information on this important work with you next year.

If you are feeling anxious, worried or uncertain we are here for you. Contact our helpline on 0300 111 4000 (9.30am to 9.30pm Monday to Friday) or email [helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk).



# Understanding your experiences

**It is vital that we listen to your needs, experiences and opinions when planning our activities, so that we can ensure that they are relevant, effective and impactful. This means we can be confident we spend the money our generous supporters raise and donate in ways that make the biggest difference.**

In 2019 we carried out our first comprehensive sight loss survey. 924 people living with or affected by inherited sight loss took the time to answer our questions.

Amongst a wealth of information about their experiences of living with a condition, we learned that:

- Only 15% were aware of their genetic diagnosis
- 53% reported that their sight loss had a severe or very severe impact on their quality of life
- Loss of confidence, anxiety and stress were the biggest emotional or psychological impacts of sight loss. Only 8% said they had experienced no impacts like these
- More than half (58%) were aware of clinical research into their type of sight loss, and 20% had participated in research. Retina UK was the top source of research information.



The survey findings helped to inform some of our key activities over the past two years:

- We created and launched 'Unlock Genetics', an accessible resource to raise awareness of genetic testing and counselling [www.RetinaUK.org.uk/genetics](http://www.RetinaUK.org.uk/genetics).
- In response to the pandemic and mental health and wellbeing needs, we upgraded our helpline system to increase capacity and improve monitoring and evaluation
- We prioritised mental health and wellbeing support (see page 6)
- We used the data from the survey as part of our submission to NICE when they considered making Luxturna available on the NHS, the first gene therapy to reach the market for an inherited sight loss condition.

Thanks to funding from Santen, we will repeat this survey in spring 2022 to ensure that we stay in touch with your needs, understand the impact of our activity and remain best placed to advocate on your behalf. Please look out for this and share your views – they are very important to us.

# Successful start to webinar series

**We have had a great response from our community to the recent webinar and information evening events with more than 300 people registering to attend.**



## Webinars

The webinar series kicked off with PhD student Elena Piotter on 24 August. Elena is a PhD student working in Professor Robert MacLaren's group in the Nuffield Laboratory of Ophthalmology at the University of Oxford. Her research is funded by Retina UK.

Her talk focused on gene therapy, CRISPR technology including DNA and RNA base editing, and why this is relevant for Stargardt disease. Stargardt disease is the most common form of inherited childhood blindness worldwide for which no current treatments exist.

New technologies, such as CRISPR, provide an exciting frontier for addressing genetic disease by allowing targeted DNA or RNA editing of pathogenic mutations.

She was followed by Dr Roly Megaw on 23 September. Roly is a Wellcome Trust funded clinical lecturer at the MRC Human Genetics Unit at the University of Edinburgh and a consultant ophthalmologist in NHS Lothian.

Roly talked about the role inflammation plays in retinitis pigmentosa (see page 5), its resulting complications and how this has informed some recent work in the lab. He went on to give an overview of these recent findings in his lab and explain how it could be an avenue to identifying novel therapies.

Finally Mr Michael Gilhooley spoke on Wednesday 27 October on the subject of Optogenetics (see page 4).

Michael is a clinical lecturer in the department of Genetics, Institute of





Dr Roly Megaw



Elena Piotter



Mr Michael Gilhooley

Ophthalmology, University College London and Moorfields Eye Hospital.

His session introduced the technique of optogenetics and its potential for development into a treatment for IRDs. Optogenetics is the process of expressing light sensitive proteins in cells, such as surviving cells in the retina, to allow them to react to light independently. It has recently been used for the first time to return some visual perspective to a patient with IRD in Paris as reported in the BBC News.

### Information evenings

Our first information evening at the end of September featured some of Northern Ireland's top Medical, Ophthalmic and Healthcare professionals with presentations on genotyping, inheritance patterns, Unlock Genetics and navigating towns and cities with sight loss.

This was followed on 13 October with a similar information evening with a focus on Wales.

All of the webinars and information

evenings were recorded and are available in video and audio formats at [www.RetinaUK.org.uk/recordings](http://www.RetinaUK.org.uk/recordings).

More webinars are planned for the coming months. You can find out more and register to attend at [www.RetinaUK.org.uk/info-events](http://www.RetinaUK.org.uk/info-events).

We do hope to return to face-to-face events in 2022. This includes our Professionals' and Annual Conferences on 8 and 9 July 2022.

If you don't currently receive emails from Retina UK, you could be missing out. Our monthly e-Newsletter contains the latest information about events, some of which are not available when *Look Forward* goes to press.

If you would like to add your name to the email list, please complete the form here: [www.RetinaUK.org.uk/keep-in-touch](http://www.RetinaUK.org.uk/keep-in-touch) or call us on 01280 821334.

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safe in-home & remote demonstrations.**



# The Big Give Christmas Challenge is back!

## And we're aiming to raise more than ever before...

2021 marks the fifth year that Retina UK has participated in the Big Give Christmas Challenge. Since 2017, you have helped us raise more than £127,000 to invest into inherited sight loss research. What an amazing achievement – thank you so much for each and every donation!

To mark this milestone, we've set ourselves our most ambitious target yet – £50,000! Between midday on 30 November and midday on 7 December you can have your donation to medical research doubled at no additional cost when you donate via the Big Give Christmas Challenge website.

**If you donate £10,  
it will be doubled to £20**

**£50 will be doubled to £100**

**£100 will be doubled to £200**

**And so on, whilst the match  
funding pot lasts.**



Make a note in your diary, set a prompt on your phone, or pop the card enclosed with this edition of *Look Forward* up on your fridge or somewhere else it will act as a reminder, and visit [www.RetinaUK.org.uk/BigGive](http://www.RetinaUK.org.uk/BigGive) between midday on 30 November and midday on 7 December for your opportunity to make twice the impact on inherited sight loss research.

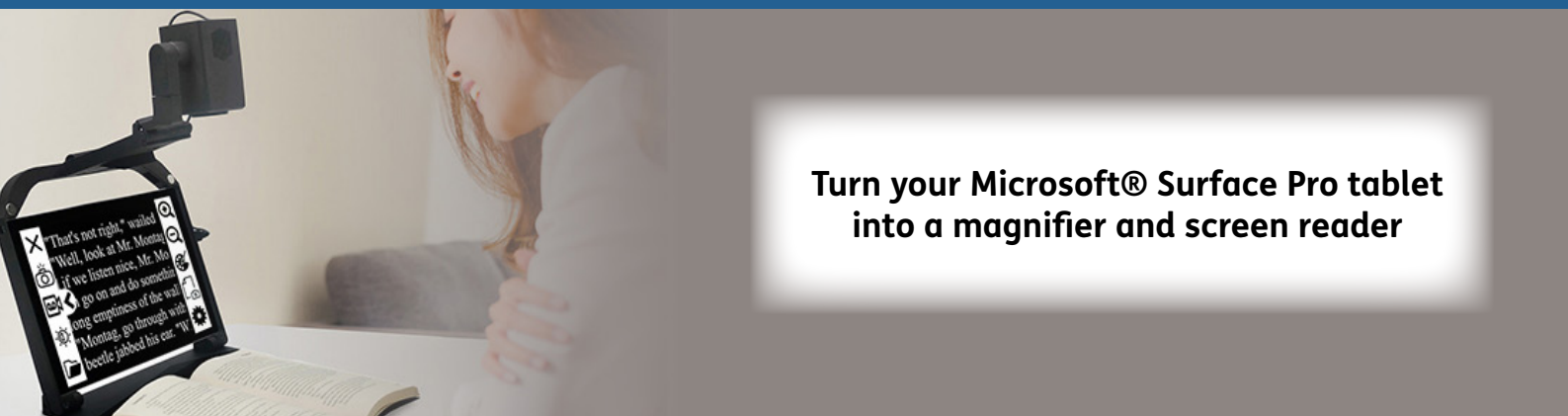
If you have any questions or would like further information, please call Deborah on 07841 004564, email [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk) or visit [www.RetinaUK.org.uk/BigGive](http://www.RetinaUK.org.uk/BigGive).

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





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The ONYX PRO is great for reading books, magazines, mail, and more! Thanks to its lightweight design and handle, you can pick it up and use it wherever you want from classroom to classroom or office to home.

Pricing starts from £2,295 without a Microsoft Surface Pro tablet or the ONYX Pro complete bundle at £3,500. Bundle includes the Onyx Pro, Surface Tablet and Keyboard, Case, 128GB Memory Card, 4-Port USB 3.0 Hub, Stylus Pen and ZoomText Magnifier Reader.

For more information or to arrange an Home or online video demonstration, please email **info@sightandsound.co.uk** or call **01604 798070** and select **Option 1**

# London Marathon returns with a cheer!

From the capital's streets to neighbourhood parks, Team Retina UK took on 26.2 miles. The cover of *Look Forward* includes a montage of images of these fantastic individuals.

This October, as our London runners stepped up to the city start line, supporters across the UK set off on their own route in the Virtual Marathon. Drawing on all of their training, they completed the distance, crossing the finish line as their families and friends cheered them on. In London, our runners were then able to unwind with a post-race massage, shower and bite to eat.

They each earned themselves a world-renowned medal, which included braille for the very first time in 2021. Together this wonderful team have raised over £59,000!

To our 2021 team and to your family, friends and colleagues who generously supported you and cheered all the way through to the final mile – we want to say a huge thank you!

## Join us for TCS London Marathon on 2 October 2022

Whether you're after a PB or need to dust off your trainers, get a place in next year's London race with us. You'll take in the cheers of the crowd as you take on the challenge of a lifetime.



*"I enjoyed running for Retina UK so much I would like to go again... what you do to help people is amazing!"*  
Neal, 2021 #TeamRetinaUK

You'll need to raise at least £2,000 so that with every step, you'll make support for people affected by inherited sight loss and pioneering research possible.

We'll be here to help you all the way to the finish line, and with our post-race reception you'll get support after the race as well! Find out more at [www.RetinaUK.org.uk/londonmarathon](http://www.RetinaUK.org.uk/londonmarathon) or call Simon, Community and Events Fundraising Manager, on 07736 925174.

# THANK YOU



Our team of trekkers took on the Peak District Challenge, together raising over £5,700! Pictured are Tracy and her team and Elena, a PhD student from Oxford University, after completing their 25km challenge.



Eileen and her family and friends arranged a folk fundraiser in Whitby. With their songs and dancing, over £220 was raised!



Over 70 walkers returned to the Isle of Wight for Hopefully to Seaview 2021 and took on a fantastic five-mile route, raising over £5,000. A huge thank you to Colin, Linda and their family and friends!

Thank you to Robert, Ronnie and customers of Six West in New Alresford for their longstanding support of Retina UK. Through their collection tin they've raised an amazing £500 this year!

Thank you for all of the imaginative ways you've fundraised so far in 2021.





Izzy celebrated her 21st birthday with a skydive, raising an incredible £1,140!

Sadly, lockdown restrictions meant Jennifer's Eye Ball was cancelled for the second time. Despite this, generous guests continued with their support and through a silent auction, prize draw and other wonderful ideas, a phenomenal £12,750 was raised.



Our Great North Run team took on the biggest half marathon in the world. Together, they raised £4,000! Pictured is Richard and Jo.



Thank you to Richard Forbes, Fourbears Consultancy Ltd, for a £600 corporate donation. Thank you for your continued support.



James and his terrific team tackled Snowdon! With kind donations from their employers to come, they're on track to raise over £3,000!

Send us your snaps to [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk) – we'd love to see them!

# Rediscover reading with RNIB

Ever since 61-year-old Gordon Anthony from Dundee was a young boy, he could always be found with a book in hand. By the age of 50, being able to read had become one of his biggest challenges after having been diagnosed with retinitis pigmentosa at 19. As he looked for new ways to adapt, avid reader Gordon discovered the Royal National Institute of Blind People (RNIB) and a love for Talking Books.



Talking Books is RNIB's version of an audio book and can be enjoyed, for free, no matter where you are. There are over 34,000 titles available and for all ages. Books come in a variety of genres from the latest best-sellers to the classics and everything in-between.

"I've never been without a book. The fact I can get audio books is a lifesaver."  
– Gordon Anthony

Talking Books began as the brainchild of Captain Ian Fraser, who lost his sight during the First World War. When the officer struggled to learn braille he thought, "If books could only talk!"

and the concept was born. He started working with RNIB in 1918 and, with time to refine the process, the first Talking Book was released in 1935.

One of the first Talking Books was Agatha Christie's 'The Murder of Roger Ackroyd' and was one of only five titles available. Today, RNIB distributes more than one million audio books to customers every year.

The service continues to grow and, over 80 years later, the legacy endures. There are now over 50,000 people across the UK currently using the service each month.

# Talking Books

As well as hosting Talking Books, RNIB Reading Services is the biggest library of its kind in the UK. The library includes braille or Giant Print on-demand books and braille music scores.

## Get books for free

Talking Books are free to all people who are blind or partially sighted. You can also access Talking Books if you have a print impairment disability when reading standard print. You don't need to be registered as sight impaired or severely sight impaired to join.

Children are eligible too. A parent/guardian can register a child and manage the account on their behalf, until they can do so independently.

There are two ways to register:

- 1. Sign up to the Online Library to get quick access to Talking Books to download to your phone or other device.**
- 2. Sign up to receive DAISY Talking Books on CD or USB by post if you do not have access to the internet.**

## Modern advances

When Talking Books first became popular it could take 10 long playing records to listen to an average novel. These records could only be played on specially designed turntables. Now, Talking Books can be played on just about anything, including smartphones, tablets, DAISY players and MP3 players.

This year, RNIB were excited to launch a more direct and instant way to access Talking Books – through Alexa-enabled devices. This new Talking Books Alexa skill allows you to search for your favourite books and manage your reading list through your smart speaker or other device – all by simple voice commands.

All you need to get started is a RNIB Reading Services account and an Amazon account registered to your Alexa device.

## Getting started

With the number of new titles growing all the time, there is no chance of boredom. Listen to Talking Books in your living room, office or wherever you choose to enjoy your books.

It's easy to join the RNIB Library and it's free. There are thousands of books you can download straight away online. And now, once you get set up and link your RNIB Library and Amazon accounts, you can simply say "Alexa, open RNIB Talking Books" to your Alexa-enabled device. To register online, visit [rnib.org.uk/onlinelibrary](https://rnib.org.uk/onlinelibrary).

For all other ways to get started with Talking Books, including CD, USB or braille and giant print formats on-demand, call the RNIB helpline on 0303 123 9999. Or visit [rnib.org.uk/books](https://rnib.org.uk/books) for more information.



# Many happy returns



**A very happy birthday to Lynda Cantor MBE, who celebrated her 80th birthday on Thursday 18 November.**

Lynda founded Retina UK (formerly the British Retinitis Pigmentosa Society and RP Fighting

Blindness) in 1975 after being told she had retinitis pigmentosa (RP) and that there was nothing that could be done.

She has continued to be the driving force behind the development of the charity and describes her proudest moment as when she was awarded an MBE in 1994.

Tina Houlihan, Chief Executive at Retina UK said: "Huge congratulations on your 80th birthday Lynda. Your passion and energy is inspiring."

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# 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.**



## Christmas cards

With artwork painted for Retina UK by artist Tina Wray, who has retinitis pigmentosa and glaucoma, these beautiful cards feature a snowman and

robin. Inside, they read 'Seasons Greetings'. Each pack contains six cards measuring 15 x 21 cm and costs £2.50. These cards were designed and printed free of charge. Production costs were kindly donated by Penbow Displays Ltd and Fast2Finish. To purchase a pack, visit: [www.RetinaUK.org.uk/shop](http://www.RetinaUK.org.uk/shop).

As you receive cards, 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 less stamps and would like to send them, we kindly ask you send them in a stamped envelope to **Retina UK, Wharf House, Stratford Road, Buckingham MK18 1TD**. Why

not ask your friends and neighbours to collect stamps too?

## Retina UK Christmas raffle

Our ever popular Christmas raffle is back! With each £1 ticket, you could win £500 or one of several fantastic prizes, all whilst supporting promising research and vital services. If you haven't received tickets, or would like to request additional ones, visit [www.RetinaUK.org.uk/raffle](http://www.RetinaUK.org.uk/raffle).

## Santa Dash

This virtual 5k is sure to get you feeling festive. Pick a playlist of Christmas hits, run a route past the best decorated houses or ask your family to join you. However you decide to run, put on your Santa hat and raise funds. Registration fee: £10.

Minimum fundraising: £100. Date:

Anytime until 25 December

All participants receive a Retina UK t-shirt or running vest and a Santa Dash medal. Visit: [www.RetinaUK.org.uk/santa-dash](http://www.RetinaUK.org.uk/santa-dash).



## Raise pounds with presents

Shopping online? Raise funds at no extra cost with AmazonSmile, EasyFundraising and more. Find out more at: [www.RetinaUK.org.uk/give-as-you-shop](http://www.RetinaUK.org.uk/give-as-you-shop).



**"I'm thrilled to be part of such a great staff team at Retina UK. I'm starting to get to grips with my new role and I have some ambitious plans for the future."**





# Meet the team

**We haven't been able to get together face-to-face for a long time (for obvious reasons) and so rather than making introductions in person, we plan to introduce members of the Retina UK team in *Look Forward* over the coming editions.**

The first of these is Mark Baxter, who many of you may already know from his work as a volunteer on the telephone helpline, the talk and support service and his fundraising challenges over the years.

Most recently he completed his fourth skydive, (from 15,000ft) followed by a head shave live on social media. He has raised more than £20,000 over the years.

He describes his involvement with the charity as follows: "For over a decade I have been volunteering my free time, knowledge and life experiences to the visual impairment and sight loss charity sector, which includes fundraising, promoting awareness and campaigning.

"I have completed fundraising challenges and running events such as the London Marathon, Nike 10km and Superhero 10km, four tandem skydives, treks across the Sahara Desert, over UK's Three Peaks, 60km

across Iceland and Tour of Mont Blanc.

"With each day that passes my eyesight gets a little worse, causing difficulties doing everyday tasks I used to do with ease. To keep some of my independence I turn to DIY; I have taught myself skills like tiling, carpentry, floor and carpet laying, and with every job I complete I share the results on social media to prove sensory disabilities do not have to impact lives and to inspire others to try new things."

Mark has recently joined the charity as Information and Support Coordinator. His specific area of responsibility is local peer support groups and the talk and support service.

*"For over a decade I have been volunteering my free time, knowledge and life experiences to the visual impairment and sight loss charity sector, which includes fundraising, promoting awareness and campaigning."*

He said: "I'm thrilled to be part of such a great staff team at Retina UK. I'm starting to get to grips with my new role and I have some ambitious plans for the future. I am hoping that my volunteering and my own experience of living with inherited sight loss will help me support others as part of my new appointment."

# Let's talk about tech: Apps and mobility

**Thanks to tech boffins, our amazing smartphones allow us to get assistance from other people and, via our cameras, they can help us with a myriad of tasks.**

*By Jonathan Abro*

Welcome to the next in my series on amazing apps that make my life that much easier. This time I'll finish up on assistance apps and move onto mobility as there is crossover between them.

*"Never share any personal information or financial and banking details on assistance apps when speaking to a volunteer just in the same way you would not share this information with a stranger on the street."*

With financial and banking help, most banks offer accessible services so contact them first.

**Be My Eyes** – an incredible free app that brings another way of keeping our independence and getting tasks done without bothering anyone while probably making someone's day by giving them the opportunity to help. There are currently over 5.2 million volunteers ready to help 341,389 of us blind and visually impaired users! Via live video calls I've used this for

something as simple as checking the colour of my socks to having the error message on my television read when it went on the blink. Specialized Help has companies from technical support to personal health and beyond, well worth exploring.

**AIRA** – Another assistance app that I've started using. AIRA employs people to help so a very different offering. There's some free usage alongside various subscription plans. Join with this link to get extra free minutes: <https://link.aira.io/ref-sghm8>.

**Mobility** – Take care when out on the streets, don't stand on the edge of the pavement when using your phone. Using gestures and voice commands while your phone is in your pocket is safest.

I'm fiercely independent and a keen walker so it is vital that I am able to find my way around London. Depending on where and how I am going, I use one or more of these apps:

**Apple or Google Maps** – on iPhone just by saying to Siri, "start walking directions to" address / postcode / landmark gets me on my way;

**Soundscape** and **Lazarillo** – announces everything around me from shop names to recycle bins, bus stops and street intersections. Integrated with maps and using Aftershockz bone-

conducting earphones to hear ambient sounds makes for great walking;

**Bus Times** – I can choose the correct bus stop, have all bus numbers at that stop, number of minutes until they arrive and all stops along each route. This takes away the need to stop every bus and ask the driver their number making bus travel so much easier;

**TfL Go** – just downloaded this app and it's an excellent journey planner for the Tube. I know my way around the Underground pretty well but wanted a backup. TfL staff are fantastic with assistance on journeys so I'm always confident on getting to wherever I need to go;

**Blue Badge** – just learnt about this app which shows where Disabled parking spaces are located. Will try when next out in a car.

There is a myriad of other mobility apps available and coupled with Be My Eyes or AIRA getting around has become a whole lot easier.

With all of these apps I still rely on one other method – I ask someone. People love to help so ask someone if you are lost or uncertain. I have had people get their maps up on their phones and walk with me resulting in a conversation and a fun encounter. I learnt about my now favourite coffee shop in The City in this way.



I hope you find this useful and it gives you some help with assistance and mobility apps. More amazing apps to follow next time...

Jonathan Abro lives in central London and is a Freelance IT Professional specialising in IT Project Management of large-scale software development and IT Accessibility for all forms of disability. He is a Trustee of VocalEyes, the Charity providing Audio Description to The Arts, a member of the London Sight Loss Council, a Tech Support Volunteer with the RNIB and a member of Retina UK. Jonathan has RP and, since being diagnosed in 1996, has lost all but a bit of his peripheral vision. He is passionate about travel with highlights including camping on the ice of Antarctica, standing on all seven continents and, to celebrate his 50th birthday (while raising research funds into RP and raising awareness of sight loss), he climbed Mount Kilimanjaro.

The information in this article should not be considered as an endorsement from Retina UK.



If you would like to make a single donation to Retina UK, please consider making use of our match funding opportunity by taking part in the Big Give Christmas Challenge from 30 Nov – 7 Dec (see page 11 for more info). If you would like to support the campaign but prefer not to donate online, please contact the fundraising team for assistance on 07841 004564 or [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk).

**Please consider donating to Retina UK through a monthly or quarterly direct debit if you can.** Regular donations provide a reliable source of income to help us to plan effectively for the future.

Complete the form below or visit [www.RetinaUK.org.uk/regular-giving](http://www.RetinaUK.org.uk/regular-giving) to sign up.

I would like to donate £\_\_\_\_\_ to Retina UK monthly/quarterly  
(delete as appropriate)

I would like my donations to be paid on the 1st/15th of the month  
(delete as appropriate)

Starting month (please allow 10 days before next collection date): \_\_\_\_\_

Account holder name: \_\_\_\_\_

Account number: \_\_\_\_\_ Sort code: \_\_\_\_\_

## Contact details

Title: Mr/Mrs/Miss/Other (please specify) \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_ Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

If you would like to receive information from us via email please tick this box

☐ This will include general updates and information about support services, events, research, fundraising and surveys. You can opt out of some or all communications, or amend your preferences by calling us on 01280 821334 or emailing [info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk).

**If you gift aid your donation, the charity will receive an extra 25p for every £1 that you give!**

☐ I confirm that I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts in that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand that the charity will reclaim 25p of tax on every £1 that I give.

Signature: \_\_\_\_\_ Start date: \_\_\_\_\_