

LOOK FORWARD



Inside: Our first ever hybrid conferences

We're all still buzzing from our recent conferences. We do hope you enjoyed them as much as we did. If you weren't able to join us, then you can watch or listen to the recordings on our website RetinaUK.org.uk/recordings. Read more on pages 4-5.

There is still plenty going on this year with information events, webinars and local peer support groups planned around the country. Read more on page 17.

Welcome to our summer edition

The generosity of our community never fails to inspire me. Whether that is financial support or time spent volunteering, we simply couldn't do what we do without you!

Inside you'll find an article showing what your financial donations have achieved so far in relation to current (or recently completed) research projects (pages 14-16).

There is also a feature about our very exciting Discover Wellbeing course, which was unveiled at our conferences (pages 22-23). I do hope you'll share the course with your friends and families.

The edition includes an update about



the results from our most recent Sight Loss Survey (pages 8-9). We'll be sharing more on how we plan to address those findings in future editions of Look Forward.

Finally, we're pleased to include a feature from our friends at VocalEyes with suggestions on ways to enjoy theatre, museums and heritage sites (pages 20-21). After two years of forced isolation, I do

hope you'll be able to get out and about a little more this summer.

Tina Garvey, Chief Executive



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

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Keeping our volunteers up-to-date

We recently held our face-to-face volunteer training event with 28 of our fantastic information and support volunteer team.



Keeping our volunteer team updated is paramount to the running of our service provision. Not only do we share Retina UK news and information, but this year we also had a session attended by Evenbreak, RNIB and Victa to share their service information.

This means that if we can't signpost within Retina UK services, our volunteers know other sight loss organisations that may be able to assist our community navigate their day-to-day life with sight loss.



Another year of successful conferences

Thank you to everyone who joined us in-person or online for our conferences this year. More than 250 people registered for our Professionals' Conference and almost 230 for our Annual Conference.



For the first time we offered a fully hybrid experience for our delegates with the choice to join us in-person at the Macdonald Burlington Hotel in Birmingham or remotely via Zoom.

Our focus in 2022 was on our new Discover Wellbeing course with candid and thought provoking presentations by Dr Mhairi Thurston and Jon Manning. You can read more about Discover Wellbeing on pages 22-23.

Some readers may remember David Bureau from the spring edition of *Look Forward* (*Riding the rollercoaster – a*

"I was really impressed how well the hybrid format worked. The 'mood' in the room was conveyed and remote access did not feel 'less or secondary'. This format enabled me to not only access information, but feel part of the community. The blending of the panels and speakers 'in person' and via zoom mirrored the delegate experience."

clinical trial experience). David joined our Annual Conference alongside Dr Mital Shah and Matias Segovia from Oxford Eye Hospital to talk about the clinical trials process from a professional and patient perspective. This prompted many questions from

We were very grateful to all of our sponsors and exhibitors for their support, including our headline sponsor Janssen, and our headline Professionals' Conference sponsor Novartis



"All sessions were useful and informative. It was good to be able to attend online. I was unable to attend in person due to other things that are happening in my life at the moment."



our delegates and is clearly an area of great interest.

Our Chief Executive, Tina Garvey gave delegates on both days a sneak peak at the findings of our 2022 Sight Loss Survey (pages 8-9). Taking part in the survey really does make a difference and directly affects the future direction of your charity, as evidenced by Discover Wellbeing, which was created in response to the findings of our 2019 survey.

Consultant ophthalmologist, Samantha De Silva spoke to professionals about

the different types of inherited sight loss conditions, including the latest research; not an easy feat in just one hour. The recordings from these sessions will be made available online and we hope will be accessed by many other members of the professional community in the future.

Davinder Kullar from RNIB discussed the option of technology for everyday living on Saturday with lots of really practical information, advice and audience participation.

Thank you to all of our speakers, exhibitors, delegates and sponsors for making our conferences such a great success.

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

We hope to return to our usual schedule of conferences taking place in September from 2023. We will update you as soon as dates are confirmed.

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Focus on a volunteer: Bhavini Makwana

Bhavini has been involved with Retina UK for many years as a service user and a volunteer. She has found the support provided to her in the past invaluable, and is an Ambassador for the charity.



Bhavini dedicates her time to empowering others with inherited sight loss to grow their confidence and live independent lives. She has volunteered on the Retina UK helpline for the past eight years and facilitates the London local peer support group. We also work with her in a professional capacity with BAME Vision, of which she is Chair.

The mum of two was diagnosed with the inherited retinal condition retinitis pigmentosa aged 17.

For 15 years she was unable to accept her sight loss and hid it from those around her, due to the fear of being judged and facing cultural barriers. But with the support of her family and Retina UK, Bhavini has come to terms with her visual impairment and has made many positive changes to her life. She received support from our helpline and attended the charity's information

events and support group meetings.

"At first I hid my sight loss because I felt ashamed and didn't want to be labelled disabled. This left me depressed and isolated. I had no one to talk to that understood or could relate to the additional challenges that I was going through as a South Asian woman going blind. The support I received from Retina UK helped me find my inner confidence and realise I could still achieve my ambitions. I felt like a huge weight had been lifted from my shoulders and I began to live again. My world began to open up with opportunities and possibilities."

"It's a fantastic charity and volunteering for them enables me to help others like me, which is really rewarding." Bhavini works for London Vision and travels independently on public transport with the support of her guide dog, Colin.

Learning from your experiences

Thank you to all those who completed our recent Sight Loss Survey – almost 700 of you took the time to share your experiences.

We carried out our first Sight Loss Survey in 2019 and used what we learned to improve our support. This included the launch of our Unlock Genetics and Discover Wellbeing resources (see pages 22-23). We also shared information with the decision-makers who agreed to fund Luxturna, the first treatment for inherited sight loss, on the NHS. This helped them to understand the day-to-day impacts of inherited sight loss.

This spring we repeated the Survey, to learn what has changed since 2019 and shape our future plans. Here are some of the key findings:

Research

Retina UK was the top source of research information for respondents, with more than two thirds (70%) of those who knew about research citing us as the source. In fact we were more than twice as likely to be mentioned as the next highest source (ophthalmologist) at 27%. We appointed Kate Arkell as our first Research Development Manager in 2019 to improve our research communication and we will continue to grow this important area of our work.

Just over half of people (54%) would like to participate in a clinical trial or some other kind of research, but haven't yet. A further 20% have participated in research, and 26% say they do not want to. We continue to make our community aware of opportunities to get involved in research, including through our Lived Experience Panel: RetinaUK.org.uk/more-info.

Genetics

Almost a third (31%) of respondents could name the gene or genetic disease type causing their sight loss – this is twice the percentage in 2019, and suggests a positive increase in the number of people who are given a genetic diagnosis. We are delighted our Unlock Genetics resource is helping people to understand their choices and is having a positive impact RetinaUK.org.uk/genetics.

Psychological impacts

Anxiety, loss of confidence and stress are the biggest emotional or psychological impacts of inherited sight loss. Only 7% say they've experienced no impacts like these. This is similar to 2019, although there has been an increase in people experiencing anxiety (78% compared with 71% in 2019). Our new Discover Wellbeing course aims to enable our community to better manage emotional impacts (see pages 22-23).

On a positive note, those who have engaged with Retina UK are less likely

to say they've experienced loneliness, isolation and depression, compared with those who have not engaged.

Diagnosis

People diagnosed more recently were less likely to believe the person giving the diagnosis understood how they felt, or to be told about ongoing support available to them. This may be an impact of the pandemic. We continue to strive to influence this and we are involved in conversations with sight loss sector partners to understand how we can work together to bring about positive change.

Signposting to Retina UK

As in 2019, most respondents were not told about the support available from Retina UK (74% were not told, and 29% said they would have liked this). This is disappointing.

Those diagnosed more recently are most likely to have found out about Retina UK from an internet search, while those diagnosed longer ago were signposted by a healthcare professional.

We will further grow our online presence and will launch a new website in 2023. At the same time, we will do more to encourage professionals to signpost to our charity.

About Retina UK

83% rate Retina UK's services as 'excellent' or 'good'. There have been increases in satisfaction and take-up

among many aspects of our information and support, compared with 2019. We are delighted to hear this and regularly ask for feedback to ensure we continue to improve our services.

- **Local groups** (including online communities) – usage is up from 18% to 21%, and satisfaction from 73% to 87%.
- **Talk and support service** – satisfaction has increased significantly (from 73% in 2019 to 83% in 2022).
- **Our helpline** – satisfaction has increased from 87% to 92%.

We couldn't have achieved any of this without our 50 information and support volunteers and we are hugely grateful for all they do.

Retina UK's future direction

Respondents were asked which of the charity's three areas of work they would like to see greatest focus on in the next three years.

Just over half (56%) said the focus should be on 'funding and promoting the search for causes and treatments for inherited sight loss'.

The remainder were split between 'providing information and support to help people manage their inherited sight loss' (23%), and 'increasing society's understanding of the needs of people with inherited sight loss' (21%).

The full report will be available soon on our website and we are considering how this influences our future work.

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When we started to develop the ClearView C, we wanted to eliminate all of the difficulties users experienced. After extensive research involving our clients, we came up with a completely new design.



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With a document placed on the movable table, the camera is positioned so that you naturally read from the top of the page. You no longer need to pull the reading table into your stomach to start reading. This design is unique to desktop video magnifiers.

Enjoy greater freedom with more working space

The left-sided C-shaped design provides you with more working space beneath the camera. Enjoy reading from broadsheet newspapers, viewing photograph albums and practical craftwork without being restricted in movement.

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on). Choose Retina UK as your charity and we'll receive donations from your shopping – our community has already raised over £2,800!

To use AmazonSmile, simply go to smile.amazon.co.uk on your web browser or activate AmazonSmile in the Amazon Shopping app (open the app and find 'Settings' in the main menu (≡). Tap on 'AmazonSmile' and follow the on-screen instructions to turn

Interested to find out about other ways to raise money as you shop online?

Visit RetinaUK.org.uk/give-as-you-shop.

Payroll Giving

Could you help make a difference each month by donating the cost of a weekly takeaway coffee through a Payroll Giving scheme?

Payroll Giving is an effortless, flexible, and tax-efficient way of supporting Retina UK through your salary or pension.

Donations are taken before tax so the charity gets more from the amount you donate.

For more information please contact Fiona Leahy, Corporate and Community Fundraising Officer, on 07736 958207 or fiona.leahy@RetinaUK.org.uk.



For example:

£1 donation would cost a standard rate taxpayer 80p, a £10 donation would cost you £8

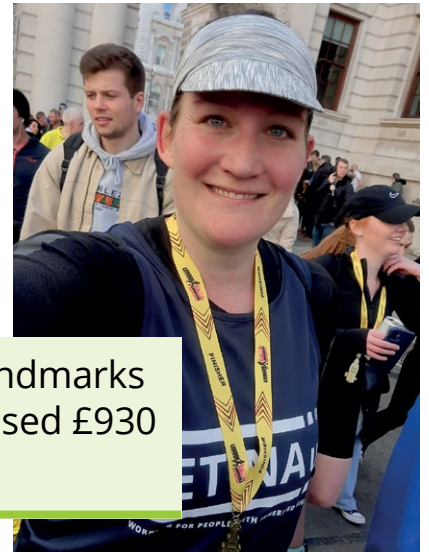
£10 could cover the costs of a call with a Helpline team member

£40 could provide a researcher with the use of a state of the art microscope for a week

Thank you ^{#TeamRetinaUK}



Mariella took on the South West Coast Path from Minehead to Poole covering an incredible 630 miles in 50 days and raised £2,239!



Liz ran the London Landmarks Half Marathon and raised £930 – thank you!

The Isle of Wight community took steps for Retina UK, completing the five mile Hopefully to Seaview sponsored walk. Thank you to Colin and Linda for organising this wonderful day and everyone who contributed. Very nearly £4,000 (as we go to print) has been raised!



Thank you to Mary, for raising £680 for research with a birthday fundraiser! Generous family and friends celebrated with donations instead of gifts.

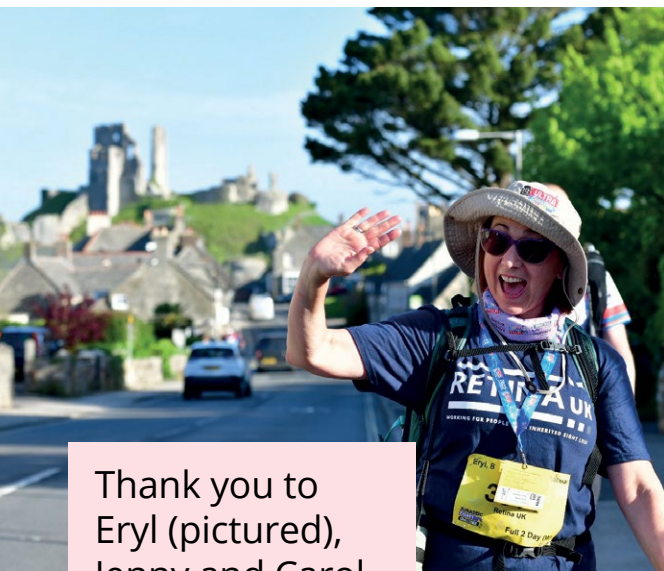


Thank you so much to newlyweds Martin and Hannah, for donating £50 in lieu of favours. We hope you had a wonderful wedding day!

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



Team MaD cycled from Land's End to John O'Groats, supporting Retina UK and several other fantastic charities. We're so grateful to the whole team for including us in this epic adventure and raising over £2,600 for Retina UK.



Thank you to Eryl (pictured), Jenny and Carol who took on the Jurassic Coast Challenge! In total, you raised almost £1,300 between you!



RideLondon returned in May! Thank you to Martin, Andrew, Tom, Nadeem, Tim and Rob who took on the 100 mile route into Essex and back to central London. Together you raised over £6,100!

Kelly and Russell, celebrated their Dad Alan's 70th birthday with a skydive in Cornwall. Together, they raised £600!



Thank you to staff and students at Oundle School, Peterborough, for raising £193 from the school's Charities Fair.

Please share your photos with us at fundraising@RetinaUK.org.uk

Your donations make progress possible

Your generous support allows Retina UK to fund the work of leading scientists who are increasing understanding of inherited sight loss and moving us closer to treatments.

Here are just some of the projects and progress you have helped make possible over the past decade.

'The Retina UK Gene Team' *Prof Robin Ali (King's College London), Prof James Bainbridge (UCL), Prof Michel Michaelides (UCL)*

For the last ten years, this team of world-leading experts have been steadily developing a pipeline of gene therapies for several forms of early-onset inherited retinal conditions. Thanks to their work, four of these potential treatments have moved into early phase clinical trials, sponsored by biotechnology company MeiraGTx, with a fifth soon to follow. The team has also treated a small number of infants with a rare and severe form of Leber congenital amaurosis (LCA4), under a special license at Great Ormond Street Hospital.

UK Inherited Retinal Dystrophy Consortium ('RP Genome Project')
Prof Alison Hardcastle (UCL), Prof Graeme Black (Manchester), Prof Susie Downes (Oxford), Prof Chris Inglehearn (Leeds)

This unique and highly collaborative



project brought together four of the largest research groups in the UK specialising in inherited retinal conditions. The team set out to investigate cases where the underlying genetic fault could not be identified.

By gathering and analysing genetic data from hundreds of people, including



those who took part in the UK 100,000 Genomes Project, the group has identified seven novel disease-causing genes, established comprehensive understanding of the role of nine further genes, and helped discover a brand new disease mechanism. Most importantly, the project has provided answers and choices for over 100

individuals and their families, and helped establish improved diagnosis for the future.

Non-viral gene therapy for Usher syndrome *Prof Mariya Moosajee (UCL/ The Francis Crick Institute)*

'Traditional' gene therapy uses viruses to carry the therapeutic genes. This recently completed project explored an alternative approach, by developing a special DNA structure to act as a gene packaging system. This "S/MAR vector" has the capacity to hold much larger genes such as the Usher syndrome gene USH2A, which cannot fit inside a virus. The new vector may also have some safety advantages.

Prof Moosajee has demonstrated that the S/MAR vector can work well to restore healthy USH2A in zebrafish and cell-based disease models. This provides a springboard to further development of this potential therapy, not only for Usher syndrome but also for other retinal conditions involving large genes, such as Stargardt disease.

Finding hidden faults in the ABCA4 gene in Stargardt disease *Prof Frans Cremers (RadboudUMC, The Netherlands)*

Faults in the ABCA4 gene cause Stargardt disease, the most common cause of childhood-onset retinal

continued overleaf

This work is only possible thanks to your generosity. If you would like to support Retina UK, please complete or scan the form on the back of this newsletter

degeneration. However, in many cases of apparent Stargardt disease, scientists have struggled to get a clear genetic diagnosis because they have been unable to find any faults in the parts of the ABCA4 gene that directly provide instructions for building protein.

Thanks to support from Retina UK, Prof Cremers and his talented team have overcome this problem by designing a very cost-effective method of scanning the entire gene, even those sections known as introns, which do not code for protein-building ingredients but nonetheless play a key role in influencing the construction of healthy protein. They have discovered 70 previously hidden genetic faults, significantly improving understanding of the underlying mechanisms of disease. They have also made this new test available for free to ophthalmologists and researchers across Europe, so that many more families can get clear answers.

Understanding the role of splicing and the PRPF31 gene in autosomal dominant RP, and moving towards gene therapy Prof Majlinda Lako, (Newcastle University)

RP is commonly caused by a fault in a group of genes that regulate the editing of unwanted passages out of a set of genetic instructions, a process known as splicing. The PRPF31 gene is a key member of this group.

Using specially developed cell-based models, derived from the skin cells of people living with PRPF31-associated RP, Prof Lako and her team were able to significantly expand understanding of the knock-on effects of faulty splicing on retinal cells.

This work has provided a springboard to a new project, for which Retina UK has just awarded funding, so that Prof Lako can look at developing a gene therapy to treat PRPF31-related RP. This is a great example of how establishing a disease model and understanding disease mechanisms can lead to therapy development.

PhD Studentships – building the research workforce of the future

We are very proud to have collaborated with the Macular Society in launching promising young scientists into a career in inherited sight loss research. A PhD is an essential first step in a research career, and involves the student undertaking a supervised project that not only produces useful outcomes but also provides the necessary scientific training and development. We are currently funding, Elena Piottter, who is at Oxford University investigating the efficacy and safety of potential gene editing approaches for the treatment of Stargardt disease. This could also be relevant to a number of other inherited retinal conditions.

Dates for your diary

Information events

The Retina UK team are looking forward to going on the road in September to meet you in Manchester, Bristol, Oxford and Hull.

This year we are going to run our Information events a little differently, taking a more informal approach to the popular events to allow for greater flexibility in the changing world we live in.

The events will run for around three hours and include light refreshments. There will be the opportunity to meet and chat with members of the Retina UK team, listen to a speaker or two, and meet others from the area who live with inherited sight loss, or support those who do.

Free to attend, the gatherings are open to anyone with an interest including families and professionals.

As always, you'll be guaranteed a very warm welcome. We hope to see you there.

To find out more visit **RetinaUK.org.uk/info-events**, email **events@RetinaUK.org.uk**, or phone us on 01280 821334.

Local peer support group meetings

Local peer support groups provide a welcoming, safe and friendly opportunity for people to meet to share experiences, tips and information.

Berkshire (online)	Tuesday 2 August
Oxford (in-person)	Thursday 11 August
Leicestershire (online)	Thursday 18 August
West Midlands (online)	Tuesday 28 August
London (in-person)	Saturday 17 September
National (online)	Thursday 29 September
Glasgow (in-person)	Wednesday 5 October
West Midlands (in-person)	Thursday 6 October
Hampshire (in-person)	Monday 10 October

For more information on upcoming meetings and to register visit **RetinaUK.org.uk/groups**.

Audio recordings from our online meetings are available on our YouTube channel: **YouTube.com/RetinaUK**.

Webinars

We've got some great webinars lined up for the autumn, starting in September with an in-depth look at Discover Wellbeing. Please visit our website for more information and to register **RetinaUK.org.uk/info-events**.

Recordings of past webinars are available online: **RetinaUK.org.uk/recordings**. These are available in video format (on YouTube) or audio (via Anchor FM). If you would prefer to receive past recordings on a CD or memory stick, just get in touch by emailing **info@RetinaUK.org.uk**.

Join #TeamRetinaUK and take over the capital!

Take steps through London's streets and raise awareness and funds. You'll help support people to lead better lives today and accelerate the search for treatments for the future.

TCS London Marathon

2 October 2022

Join us for the iconic TCS London Marathon 2022. Soak up the incredible atmosphere as you run from Blackheath to The Mall on a route that includes Tower Bridge, Big Ben and Buckingham Palace with the world-famous crowds cheering you on! You'll get dedicated support all the way to the finish line with fundraising top tips, a personalised running vest and invitation to our post-race reception.

Charity place:

£100 registration fee - £2,000 fundraising

Application deadline: 8 August 2022

RetinaUK.org.uk/london



Thames Path Challenge

10-11 September 2022

England's greatest river provides a fantastic backdrop for this challenge. Over 3,000 adventurers will join the Putney Bridge start, and the full 100 km route heads upstream all the way to Henley along the famous Thames Towpath. The routes goes through Richmond, Hampton Court, Runnymede, and Windsor, with some wonderful historic scenery en-route to a riverside finish line. You'll get full support & hospitality all the way – and with 50 km and 25 km distance options also available.

Charity sponsorship place:

Full Challenge:

£30 registration fee - £595 fundraising

Half Challenge:

£20 registration fee - £395 fundraising

Quarter Challenge:

£10 registration fee - £250 fundraising
(other pricing structures also available)

Sign up deadline: 6 August 2022

RetinaUK.org.uk/TPC



Thames Bridges Trek

10 September 2022

Join 2,000 walkers and trek across the Capital. Setting out from the Putney Bridge start, you'll head east towards the City, zig-zagging over 16 historic bridges – each with its own fascinating story – and a mid-point rest stop at The Oval Cricket Ground for some snacks and drinks. 25 km later, it's a party style finish line celebration in Southwark Park past the final crossing – the majestic Tower Bridge!

Charity sponsorship place:

£10 registration fee - £250 fundraising (other pricing structures also available)

Sign up deadline: 6 August 2022

RetinaUK.org.uk/TBT



Photos can be a wonderful memento for our team and they help us to advertise our events in future – allowing Retina UK to raise more, and do more of what we do best. If you're a dab hand with your DSLR, local to London and can volunteer a few hours of your time on 2 October, we'd love to hear from you. Call Simon on 07736 925174 or email simon.taylor@RetinaUK.org.uk.



Royal Parks Half Marathon

9 October 2022

This stunning central London half marathon takes in some of the capital's best landmarks on closed roads, and four of London's Royal Parks! With sustainability a key feature, you'll find FSC certified wooden medals and race shirts made from recycled bottles, amongst other innovative ideas.

Charity place:

£15 registration fee - £400 fundraising

Sign up deadline: 5 August 2022

RetinaUK.org.uk/royal-parks

Join the team from your street

2 October 2022

The virtual TCS London Marathon lets you join our team wherever you live. You'll have the full day to complete your 26.2 miles. Whether you chose to take this on as a solo runner or find a friend to walk alongside, with the virtual race it's your run, your way.

Charity place:

£14 registration fee - £165 fundraising

Sign up deadline: 12 September 2022

RetinaUK.org.uk/london

Get out and about this summer with VocalEyes

Enjoy the return of many audio-described theatre, arts, and heritage events this summer as described in this feature from VocalEyes.

VocalEyes believes blind and visually impaired people should have the best opportunities to enjoy arts and heritage. They work with theatres, museums and heritage sites to bring art and culture to life through audio description. In theatres, audio description is usually a live (sometimes pre-recorded) verbal commentary, which fills in the gaps that you may miss due to visual impairment. This can include facial expressions, explaining visual jokes, costumes and props. A touch tour is also run prior to the performance where you will get the opportunity to go on stage, explore the set, props and costumes and meet some of the cast. They audio describe all genres from plays, musicals, ballet, circus, at outdoor venues and festivals. At museums, galleries and heritage sites, audio description can be a live audio-described tour and workshop or a pre-recorded audio guide with information about the exhibits, as well as navigation information to help you access the venue independently.

VocalEyes also provides visual awareness training to venues across the UK so even if there's not a dedicated audio-described tour at a venue that you'd like to visit, staff are able to welcome and assist you, and



Eileen's friend Phillip crossing the stepping stones in the Japanese garden at Newstead Abbey the ancestral home of Lord Byron

given sufficient notice may also be able to find a guide to support you. It's always good to contact a venue in advance to find out what access support they can provide.

Many venues offer concessionary tickets for access bookers. This can be discounted tickets for you and a companion or a free companion ticket. Check when making your booking what concessions are available. Theatres often have their own access scheme that you may be required to register with.

“Whenever we want to visit a venue, I ring in advance and explain I’m bringing a blind person to their venue and ask what facilities they have for us. I ask for a private guide; someone enthusiastic about their venue, and willing to take the time and trouble to show us around.”

To find out what’s on this summer, visit the What’s on pages of VocalEyes’ website vocaleyes.co.uk/whats-on. You can search for audio described events in your region, by type, date, or keyword. They re-started producing their quarterly What’s On guide, packed full of audio described events throughout the summer. The guide is available to subscribers in clear print, braille, USB audio and available to download in large print or audio. Subscribe to VocalEyes to receive the guide in your chosen format. You’ll also receive monthly email newsletters with highlights of what’s on for the month ahead and other key news.

Please visit their website at vocaleyes.co.uk, follow them on Facebook and

Twitter @VocaleyesAD, Instagram @VocaleyesAudioDescription. Or email enquiries@vocaleyes.co.uk.

Retina UK supporter, Eileen Gandy is on a mission to raise awareness of the needs of blind and partially sighted people at local venues:

“Whenever we want to visit a venue, I ring in advance and explain I’m bringing a blind person to their venue and ask what facilities they have for us. I ask for a private guide; someone enthusiastic about their venue, and willing to take the time and trouble to show us around.

“As we enter each room, I ask the guide to set the scene, before explaining about the exhibits. At a recent visit to the Museum of Timekeeping they left some of the clocks to be wound up while we were there. They also prepared some clocks to chime during our visit and made several items available to touch.

“The highlight of a visit last year to Cresswell Crag archaeological site was when they opened the gated entrance to a cave. We sat on logs of wood in front of a make-believe fire while they explained the history of the place, regularly giving us items we could touch.

“It’s this type of attention to detail that makes the visit all the more meaningful and worthwhile.”

Helping you manage the emotional impacts of

Retina UK has developed an innovative course to help those living with inherited sight loss develop an awareness of emotional wellbeing and practical skills to actively cope with life's ups and downs.

The course has been shaped by many people affected by inherited sight loss conditions.

We created it in response to the findings of our 2019 Sight Loss Survey which revealed that only 8% of respondents had experienced no emotional or psychological impacts. Our most recent survey shows this is still the situation (see pages 8-9).

Denise Rawden, Information and Support Manager, explained wellbeing is how comfortable, happy and healthy we are: "The findings of our Sight Loss Survey and the nature of calls and emails to our helpline show us that many in our community experience poor emotional wellbeing. Understandably, the inherited and progressive nature of the conditions can take a real toll at different times in people's lives," she explained.

"We want to encourage open conversations about emotional health alongside the physical impacts of living with an inherited sight loss condition.



"Our Discover Wellbeing course will give people the tools they need to become more aware of their emotional health and practical skills to maintain positive wellbeing."

There are three main courses to choose from and all are free to access:

Early stages – understand your feelings of apprehension and take positive practical steps to prepare for the future.

Living with change – understand your feelings of loss, adapt to a reduction in

This project has been made possible thanks to sponsorship from Janssen and grant funding from Novartis.

sight loss



sight and take practical steps to live a positive life today.

Supporting others – learn practical skills and access tools to look after yourself whilst learning how to support others. This is designed for family members and professionals.

We are delighted that Dr Mhairi Thurston, a senior lecturer in counselling at Abertay University has supported this work. She lives with retinitis pigmentosa and is an expert in the social and emotional effects of acquired sight loss.

Mhairi said: “I was thrilled to be invited to be involved in the project because I think it’s really important that we start talking about the impact of sight loss on mental health. There is a lot to get your head around when you are first diagnosed with sight loss and when your head is in the right place life becomes much easier.”

We worked in partnership with Arthur Ellis, a mental health and wellbeing organisation to create the new resource. Founder Jon Manning said: “We worked closely with many people living with inherited sight loss to develop the course and we are grateful to all those shared their experiences with us.

“The course will guide people through the five stages of inherited sight loss and provide psychological and practical tools to enable them, their families, friends and professionals to provide the best support possible.”

We are training a number of team members to become Wellbeing volunteers. They have lived experience of inherited sight loss and their role is to provide encouragement and guide people through the course.

More information on the course, and a link to register can be found at **RetinaUK.org.uk/wellbeing** or email **wellbeing@Retinauk.org.uk**.

Help build the research workforce of tomorrow!

Donate today to help students like Elena, make life-changing discoveries in the future!



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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.

It is often cheaper to contact you via email – please tick the box if you're happy for us to contact you via email ☐

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