# E-Newsletter - October 2020

The next edition of Look Forward is currently being prepared. Don't forget that it is available in print, digital (Word and PDF), audio and braille formats. You can read about our new memory stick trial further on in this newsletter. If you'd like to change the format you receive it in, or if you would like us to send it to you via the Articles for the Blind scheme (which means we don't have to pay the postage) just email info@RetinaUK.org.uk.

Our Research Manager, Kate, recently interviewed Andrew Webster, Dr Nikolas Pontikos and Nick Nettleton about their new MyEyeSite app which aims to give people with living with rare eye conditions ownership of their own digital medical data. You can listen to it below or on Apple Podcasts, Spotify and Google Podcasts.

<https://anchor.fm/retina-uk/episodes/The-new-MyEyeSite-application-and-how-it-will-give-people-living-with-rare-eye-conditions-ownership-of-their-own-digital-medical-data-ekloe3>

## Christmas Raffle

## Many of you will have received your Retina UK Christmas Raffle tickets in the post recently – if you haven’t, and would like to request some or find out more – visit our website: [www.RetinaUK.org.uk/raffle](http://www.retinauk.org.uk/raffle). You could win £500 in time for Christmas, or one of several other fantastic prizes – all whilst supporting vital services and medical research.

## Usher Kids UK family Zoom calls

Usher Kids UK are holding a series of family Zoom calls this autumn/winter, providing families of children living with Usher syndrome with tailored information and support. The next calls are scheduled as follows:

* **Wednesday 25 November**: <https://www.eventbrite.co.uk/e/virtual-get-together-for-parentcarers-of-children-with-usher-syndrome-tickets-121239437421?aff=erelexpmlt>
* **Wednesday 27 January**: <https://www.eventbrite.co.uk/e/virtual-get-together-for-parentcarers-of-children-with-usher-syndrome-tickets-121240909825?aff=erelexpmlt>

They will cover a range of topics including mental health, educational provisions, and research.

For more information, please visit the Usher Kids UK website: [**www.usherkidsuk.com**](https://www.usherkidsuk.com/).

## Charles Bonnet Syndrome patient information event

Join the online Charles Bonnet Syndrome Patient Information event on Monday 16 November, 10.00am - 12.30pm.

Hosted by University College London for Esme's Umbrella, this is to mark 5 years since the launch of Esme's Umbrella and 300 years since the birth of Charles Bonnet.

There will be updates on research results, ongoing research and proposed research; new support initiatives for people living with CBS; and how awareness is rising globally.

Find out more and register to attend at [**www.eventbrite.co.uk/e/charles-bonnet-syndrome-patient-information-event-tickets-124261173515**](https://www.eventbrite.co.uk/e/charles-bonnet-syndrome-patient-information-event-tickets-124261173515).

## Thanks to you ... the difference we made in 2019

Our 2019 impact report is now ready, and we are delighted to share it with you. If you supported us last year through donations, fundraising or volunteering, we are so grateful.

The report is available in [**PDF**](https://retinauk.org.uk/wp-content/uploads/2020/09/ImpactReport-2019-WEBSITE.pdf), [**Word**](https://retinauk.org.uk/wp-content/uploads/2020/09/ImpactReport-2019-WEBSITE-WORD.docx)and [**audio**](https://anchor.fm/dashboard/episode/ek0nil)formats: [www.RetinaUK.org.uk/publications](http://www.RetinaUK.org.uk/publications).

## Virgin Money London Marathon 2021

Look ahead to next year and set yourself a challenge!

Take on the world-famous 26.2 mile route next October to help people affected by inherited sight loss. As part of our team you'll get dedicated support through to race day, a running vest, post-race reception, access to our Strava running club and more!

Find out more and apply for a place: [**www.RetinaUK.org.uk/londonmarathon**](http://www.retinauk.org.uk/londonmarathon).

## Volunteers needed to test new memory stick pilot

We have been told by many members of our community that they no longer have a CD player and that the devices they now use have a USB slot for a memory stick.

Thanks to sponsorship from Janssen, we will be piloting the distribution of Look Forward on memory stick (instead of CD) this November. The first group will be relatively small; a maximum of 25 people.

The plan is to send out the memory stick with the latest edition of Look Forward loaded onto it in a reusable pouch. When you have finished listening, simply return the stick to the pouch and return it to us. For those familiar with Calibre Audio Library's system, this will be very similar.

If you are interested in joining the pilot group, please email **jane.russell@RetinaUK.org.uk**. Please note, the returnable memory sticks are only available via the Articles for the Blind service so if we don't already have it, we do need your permission to send post to you marked in this way.

If you are able to access the Internet, you may be interested to know that back issues of Look Forward are available on our Podcast channel: [**https://anchor.fm/retina-uk**](https://anchor.fm/retina-uk). It is available on Apple Podcasts, Google Podcasts, Spotify and more.