# E-Newsletter - March 2021

# Whilst brighter days may hopefully be on the horizon for many of us, some members of our community may be struggling even more as things start to open up and some form of normality returns. Our Helpline (0300 111 4000) has heard from people who have lost confidence and mobility skills over the lockdown periods. We are here for you if you need us. You can call on 0300 111 4000 or email helpline@RetinaUK.org.uk. All of the volunteers on our Helpline are affected by inherited sight loss.

## Retina UK Annual Conference

If you haven't already registered to attend our Annual Conference on Saturday 17 April (10.00am - 2.45pm), there's still time. The 2021 Conference will be held entirely online and we hope that will mean that many more of you will be able to join us.

Our stellar line up of speakers will give presentations on all things genetics. We will be joined by Alison Hardcastle, Professor of Molecular Genetics at University College London Institute of Ophthalmology, Georgina Hall, Consultant Genetic Counsellor at Manchester Centre for Genomic Medicine and Dr Samantha de Silva, Consultant Ophthalmologist, Oxford Eye Hospital.

We're also really excited to be launching the new Retina UK 'Unlock Genetics' website at the Conference. The purpose of the site is to provide clear, accessible and balanced information to help you to understand why getting a genetic test could be important and to equip you with the tools needed to request a test, if that is right for you and your family.

Register Now at www.Retinauk.org.uk/annual-conference/.

## Sight Village Online

Following the success of the Sight Village Online Information event in January, QAC will be hosting another event from 20 - 22 April.

It will take place LIVE via YouTube (a YouTube account is not required). Please register via their website: <https://www.qac.ac.uk/>. If you'd prefer to register by phone, please call 0121 803 5484.

## The Big Step Challenge

Take steps for Retina UK this spring with The Big Step Challenge. Team up with a friend or family member and take on 25,000 steps between you each day for 25 days. Share what you’ve done to receive your medal!

Find out more and register here: [www.Retinauk.org.uk/big-step-challenge/](http://www.Retinauk.org.uk/big-step-challenge/).

## Update on local group meetings

Our Local Peer Support Group meetings are going from strength to strength. Our London group met again online on Saturday 20 March. Bhavini Makwana, who chairs the group, was joined by 35 members of our community to hear from guest speakers Davinder Kullar and Jonathan Abro talking about technology tips, tricks and useful apps. It was an enjoyable session with lots of valuable information from our experts and also some great tips shared by the group.

Our Somerset Group also met online on Monday evening 22 March – this month we heard about the plans that Somerset Sight have as we start to emerge from lockdown, and had a great presentation from Elena Piotter (a Retina UK PhD researcher), who spoke about the research project she is part of trying to find ways to use a modified style of CRISPR to treat people with Stargardt’s. She was really well received and was very excited to meet members of our community.

It was lovely to welcome new people to the groups, if you haven’t attended a group yet, we would encourage you to do so – especially since travel isn’t an issue! If you are interested please get in touch and we can ensure you hear about upcoming meetings. Email: services@retinauk.org.uk.

## Encouraging results from ProQR USH2A clinical trial

Biotechnology company ProQR has announced encouraging results from its phase 1/2 clinical trial of an innovative treatment for sight loss caused by faults in a specific section of the USH2A gene.

Mutations in the USH2A gene cause a certain type of Usher syndrome, where there may be hearing and balance issues alongside sight loss, as well as “non-syndromic” retinitis pigmentosa, where only vision is affected.

Errors in a particular section (exon 13) of the USH2A gene are thought to be associated with more than 16,000 cases of inherited sight loss, and there is currently no treatment available. ProQR has developed a special molecular “patch” that covers up the faulty section of genetic code, enabling retinal cells to use the rest of the USH2A genetic information to produce functional USH2A protein.

Read the full article on our website [www.Retinauk.org.uk/research-news](http://www.Retinauk.org.uk/research-news).

## Which benefits might I be able to claim?

There are many helpful benefits and support available to make life easier if you're blind or partially sighted. The RNIB provides lots of information on the benefits you may be entitled to and how to make a claim: <https://www.rnib.org.uk/advice/money-benefits-finance>.

They also provide a benefits calculator which can tell you exactly which benefits you could be entitled to: <https://rnib.entitledto.co.uk/home/start>.