# E-Newsletter - April 2021

It's been a week since our very first online Annual Conference and what a Conference it was. Your feedback has been overwhelmingly positive and we are very grateful to everyone who returned the very short online survey. If you haven't already completed it, we really do value your feedback. It will help us to shape future events, particularly now that restrictions have started to be lifted. You can find it here: <https://www.surveymonkey.co.uk/r/YJ6Y8TD>.

The Conference recordings are now available in both audio and video formats. You can find them on our website: [www.RetinaUK.org.uk/recordings](http://www.RetinaUK.org.uk/recordings).

We said farewell to our Chairman, Don Grocott when he retired on Saturday after a 10 year tenure. He will be greatly missed and has promised to stay in touch. He is succeeded by Martin Kirkup: You will hear more from Martin in the coming months.

## Unlock Genetics

We were excited to launch the new Unlock Genetics website at our Annual Conference on Saturday. It aims to increase understanding of genetic testing and counselling in the inherited sight loss community. Find out more at [www.RetinaUK.org.uk/genetics](http://www.RetinaUK.org.uk/genetics).

We will feature an in-depth article about Unlock Genetics in our next edition of Look Forward. If you don't already receive it, please indicate your preferences here: www.RetinaUK.org.uk/look-forward.

## Helpline upgrade: one year on

In the 12 months since we upgraded the helpline and introduced our new local rate number, calls have increased by over 25% on the same period the year before.

Our volunteers are finding the system much easier to operate with positive comments from all of our team.

‘The new system is much easier to use and I particularly like the new low cost number – it’s easy to remember and will mean that our community won’t be worried about the cost of calling us when they need to reach out for help’

We have also introduced a feedback survey at the end of the call. Of those who completed the survey, 100% have said that they would use the Retina UK helpline again or recommend it to others who may benefit.

‘Thank you, it was an excellent service, thank you for your help!’, ‘It’s very nice to have Retina UK there to answer any questions or problems that may be experienced by people who have RP like myself. Thank you to all the volunteers and the people who keep us informed’

Our helpline is available to family members and professionals as well as those living with an inherited retinal dystrophy. You can choose to speak to one of our volunteers on the phone or send an email. Our volunteers are themselves living with an inherited sight loss condition, so have a good understanding about day-to-day queries and issues. They can offer a listening ear, hints, tips, guidance, support and signpost relevant information. Please do get in touch, we’re here to support you – call 0300 111 4000 or email: helpline@RetinaUK.org.uk.

## Captain Tom 100 - one week to go!

We’re proud to be part of the Captain Tom 100 to celebrate the life and legacy of Captain Sir Tom Moore. Join Team Retina UK and take on a challenge around the number 100 anytime and anywhere over Captain Tom's birthday weekend on 30 April to 3 May.

Run for 100 minutes, bake 100 cakes or walk 100 laps of your neighbourhood - however you choose to take part you’ll be helping people with inherited sight loss. Create your fundraising page today: <https://captaintom100.justgiving.com/get-involved?charityId=182518>

## Local groups: dates for your diary

We will be holding an online local group meeting for the Birmingham area on Thursday 13 May from 6.30pm - 7.30pm.

Consultant Ophthalmologist Rupal Morjaria has kindly agreed to join us to talk about RP gene therapy and genetics. She is the retinal genetics lead in her department and experienced in all aspects of Ophthalmology with a specific interest in medical retina diseases including diabetes, macular degeneration, uveitis and retinal genetics.

We're also planning a London Local Group meeting on Saturday 15 May from 11.00am - 1.00pm. More details to follow on this one.

You can find out more about our local group meetings on our website: [www.RetinaUK.org.uk/groups](http://www.RetinaUK.org.uk/groups).