# E-Newsletter: February 2024

This e-Newsletter is also available in [audio format](https://podcasters.spotify.com/pod/show/retina-uk/episodes/e-Newsletter-February-2024-e2fqsqn).

Webinar: How your donations make a difference

## Date and time: 11/04/2024 from 19:00 to 20:15

## Place: Online

Join Research Development Manager, Kate Arkell as she speaks to our latest research grantees about their projects.

* PhD studentship: Dr Matteo Rizzi, UCL Institute of OphthalmologyInvestigating photopsia and photophobia in Stargardt disease.
* **PhD studentship: Chloe Brotherton, Edinburgh University**Understanding why different RPGR gene mutations can lead to different diagnosis.
* **PhD studentship: Gabriel Velichkova, UCL Institute of Ophthalmology**Investigating Stargardt disease as a target for gene repair.
* **Professor Jacqueline van der Spuy, UCL Institute of Ophthalmology**The consequences of toxic accumulation of a molecule called cGMP in Leber congenital amaurosis (LCA).
* **Professor Jane Sowden, UCL Great Ormond Street Institute of Child Health**Restoring some vision at the later stages of sight loss in advanced retinitis pigmentosa (RP) using a stem cell patch.

To register, follow this link: [Webinar: In conversation with our new research grantees - Retina UK](https://retinauk.org.uk/event/webinar-grantees2024/)

## 5K A Day in May

5K A Day In May 2024 is a new Retina UK virtual campaign to tie in with National Walking Month 2024.

It’s simple – donate £5 to enter, walk or exercise 5K a day (or walk 5,000 steps as an alternative) in May, and then fundraise for Retina UK.

Find out more and sign up here: [RetinaUK.org.uk/event/5k-a-day-in-may-2024/](http://www.RetinaUK.org.uk/event/5k-a-day-in-may-2024/).

Every single penny that we raise goes towards supporting those who are living with inherited sight loss. Now that longer, brighter days have finally arrived, it’s a great activity for teams to get involved in, stay fit and also raise much-needed funds at the same time.

### Job vacancy: Helpline and Information Coordinator – part-time 21 hours per week

We’re extremely proud of the support we offer to those living with inherited, progressive sight loss. Our services provide a safe place to find accurate information about inherited retinal conditions; to ask questions and share thoughts, feelings and anxieties with those who genuinely understand.

We are growing our information and support service and looking for two Helpline and Information **Coordinators to join our team** working 21 hrs per week.

You will be the first point of contact for our telephone helpline, actively listening to callers, assessing their needs and providing high quality information and signposting to Retina UK’s resources including our amazing team of lived experience volunteers who will provide emotional support and guidance as well as coping strategies.

[Find out more about this job vacancy](https://retinauk.org.uk/about-us/work-for-us/)**.**

## Conferences 2024: Save the date

You told us you'd like us to move our Annual Conference north and we've done just that. We are excited to announce that this year’s Annual Conference and AGM will be held both in person, and online on Saturday 28 September in Manchester. The in-person venue is the Pendulum Hotel, Manchester (M1 3BB). Our Professionals’ Conference will be held on Friday 27 September at the same venue.

We are planning a fantastic line-up of speakers and topics for both events. In the meantime, please save the date and complete the short registration form on our website if you would like us to contact you when full delegate registration opens:

* [RetinaUK.org.uk/annual-conference](http://www.RetinaUK.org.uk/annual-conference)
* [RetinaUK.org.uk/prof-conf](http://www.RetinaUK.org.uk/prof-conf)

## Research News

### Vitamin A supplements provides no vision benefit to RP patients

This new finding comes from analysis of data from a clinical trial conducted between 1984 and 1991. The trial originally found that taking vitamin A supplements slowed loss of vision in people with RP. The study also noted that taking vitamin E supplements increased the speed of vision loss.

To read the full article, please visit our website: [Vitamin A supplements provides no vision benefit to RP patients - Retina UK](https://retinauk.org.uk/news/vitamin-a-supplements-provides-no-vision-benefit-to-rp-patients/)

Gene Therapy improves functional measures in XLRP

Beacon Therapeutics announced positive results from their phase 2 gene therapy trial for X-linked retinitis pigmentosa (XLRP) caused by mutations in the RPGR gene. The treatment, called AGT-501, is an injection delivered to the retina, and led to improved visual function and retinal sensitivity in some trial participants with X-linked RP after a 12 month follow up.

To read the full article, please visit our website: [Gene Therapy improves functional measures in XLRP - Retina UK](https://retinauk.org.uk/news/gene-therapy-improves-functional-measures-in-xlrp/)

## Retina UK Weekly Lottery

Thank you so much to everyone who has already signed up to our new weekly lottery, it’s been fantastic to see so many of our supporters joining in with the fun. If you haven’t already, you can sign up from just £1 a week and be in with a chance to win £25,000!

Visit [RetinaUK.org.uk/lottery](https://retinauk.org.uk/get-involved/donate/lottery/)or call 01280 815900 now to sign up the lottery. 18+ only.

## TCS London Marathon 2024

This year’s TCS London Marathon is taking place on Sunday 21 April and we’d like to wish our 22 incredible #TeamRetinaUK runners the best of luck! As a team, they’ve raised over £50,000 already for Retina UK and we couldn’t be more grateful. You can follow the race across the BBC and you’ll hopefully be able to spot one of our inspirational runners! Interested in running for Retina UK in 2025? [Get in touch](mailto:james.clarke@retinauk.org.uk).

## Upcoming Local Peer Support Group meetings

Chat with other people living with inherited sight loss at one of our free upcoming Local Peer Support Group meetings.

* [Manchester](https://retinauk.org.uk/event/manchester-local-peer-support-group/) – Online - Thursday 11 April - 7.00pm to 8.30pm  
  Guest speaker Graham Page, Technology Officer in the employment team at Thomas Pocklington Trust.
* [‘Talking’ Travel](https://retinauk.org.uk/event/edinburgh-local-peer-support-group/) – Online - Tuesday 16 April - 7.00pm to 8.00pm

Guest speaker Gavin Neate, Founder & CEO of WelcoMe, a web-based customer service tool to give disabled people a method to share their accessibility requirements when visiting different venues.

* [West Midlands](https://retinauk.org.uk/event/west-midlands-local-peer-support-group/) – In-Person - Saturday 20 April - 10.45am  
  The group will be visiting the Birmingham Museum & Art Gallery for their Victorian Radicals Exhibition.
* [National (Spring)](https://retinauk.org.uk/event/national-peer-support-group/) – Online - Wednesday 24 April - 6.45pm to 8.30pm  
  Training Coordinators, Kate Adams and Geraldine Fitzpatrick from The British Red Cross who will be leading an Adult First Aid Workshop for us.
* [London & South East](https://retinauk.org.uk/event/london-south-east-local-peer-support-group/) – Online - Saturday 18 May - 11.00am to 1.00pm  
  Guest speaker Rory Field, CEO of London based charity, Metro Blind Sport.
* [\*Coming Soon\* ‘Talking’ Home & Garden](https://retinauk.org.uk/information-and-support/services/local-peer-support-groups/coming-soon/) – Online - Date TBC  
  Please register your interest for this group if you would like to join us to share your tips, hints, stories and experiences around all things home & garden.

## Sensing Nature Guide

Our friends at Westonbirt Arboretum are looking for volunteer guides for their Sensing Nature walks.

To find out more, email [volunteer.westonbirt@forestryengland.uk](mailto:volunteer.westonbirt@forestryengland.uk)or call 0300 067 4847.