

# LOOK FORWARD



**INSIDE:  
FOCUS ON  
FUNDRAISING**

Your help has never been more needed to support the research we are funding. You can find out more about how the pandemic has affected our research projects on page 18.

We are so fortunate at Retina UK to have such active, enthusiastic and dedicated fundraisers supporting our work. One such individual is James Clarke who has raised tens of thousands of pounds. His latest project, a skydive, is pictured here, which he describes as a once in a lifetime experience. This edition of our newsletter also includes information about our Christmas Raffle (page 17) and The Big Give Christmas Challenge (page 7).



/RetinaUKcharity



@RetinaUK



@Retina\_UK

*Please pass this newsletter on to others when you've finished reading it*

# Rising to the challenge

How is it November already? The nights have been drawing in so fast and I know that this time of the year can be hugely challenging for many of our community because of reduced night vision. Don't forget that our Helpline volunteers are here for you if you need them, as is our Talk and Support service (see pages 14-15).



Commission) because of the pandemic. We plan to hold it in April 2021 alongside our Annual Conference. More information will be available in February. In the meantime, our Annual Report has been published and is available on our website: [www.RetinaUK.org.uk/publications](http://www.RetinaUK.org.uk/publications).

I mentioned in our last newsletter that we were successful in our application for a BBC Lifeline television appeal. I want to thank you all for your support in donating and sharing it with your friends and families. The awareness raising it resulted in has been praised by many of you on our social media channels. Thank you. We interviewed presenter Amar Latif recently about his sight loss and his career so far. You can read the resulting article on pages 4-5.

Our Annual General Meeting (AGM) has been delayed this year (with full support from the Trustees and the Charity

If you have an interest in helping to shape the strategic future of our charity as we head towards our 50th anniversary in 2026, we are looking for volunteer Trustees to join our Board. Find out more on page 21.

I know that all of the team will join me in saying how proud we are of Retina UK and our wonderful community in this most unusual of years. Thank you again.

Tina Houlihan, 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.

Retina UK, Wharf House, Stratford Road, Buckingham MK18 1TD

E: [info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk) · T: 01280 821334 (Office) · T: 0300 111 4000 (Helpline)

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*This newsletter has been funded through sponsorship by Janssen. Janssen has not been involved in the production, review or distribution of this material.*

# Conferences 2021

As advised in our last edition of Look Forward, our Annual and Professionals' Conferences have been rescheduled to April 2021.



Please continue to register your interest in attending to receive an update when registration opens:

Professionals' Conference (16 April): [www.RetinaUK.org.uk/prof-conf](http://www.RetinaUK.org.uk/prof-conf)

Annual Conference (17 April): [www.RetinaUK.org.uk/annual-conference](http://www.RetinaUK.org.uk/annual-conference)

The safety of our community is of the utmost importance and, with continuing uncertainty about restrictions due to the pandemic, it is looking increasingly likely that these conferences will be held online rather than face-to-face.

## British Wireless for the Blind Fund (BWBF)

Our friends over at BWBF have developed a free app which allows users to access talking newspapers and associated magazines (split regionally and alphabetically) on a mobile device. Download the Talking Newspaper app from Google Play and the App Store (just search BWBF).

They are currently developing speech

apps (a little like the Amazon Alexa facility) and are looking for people willing to take part in testing.

They would like you to provide detailed feedback on how accessible the app is, what you do and don't like and what you would change. If you are interested in being part of this please email [dave@blind.org.uk](mailto:dave@blind.org.uk) who would be delighted to hear from you.



# 'I can still find so much happiness

In the world of sight loss, some people really don't need much of an introduction. This can certainly be said of Amar Latif who recently presented our BBC Lifeline appeal. He is the founder of the travel business, Traveleyes and is carving out a career as a presenter on television, including reaching the semi-finals of *Celebrity MasterChef* this year.

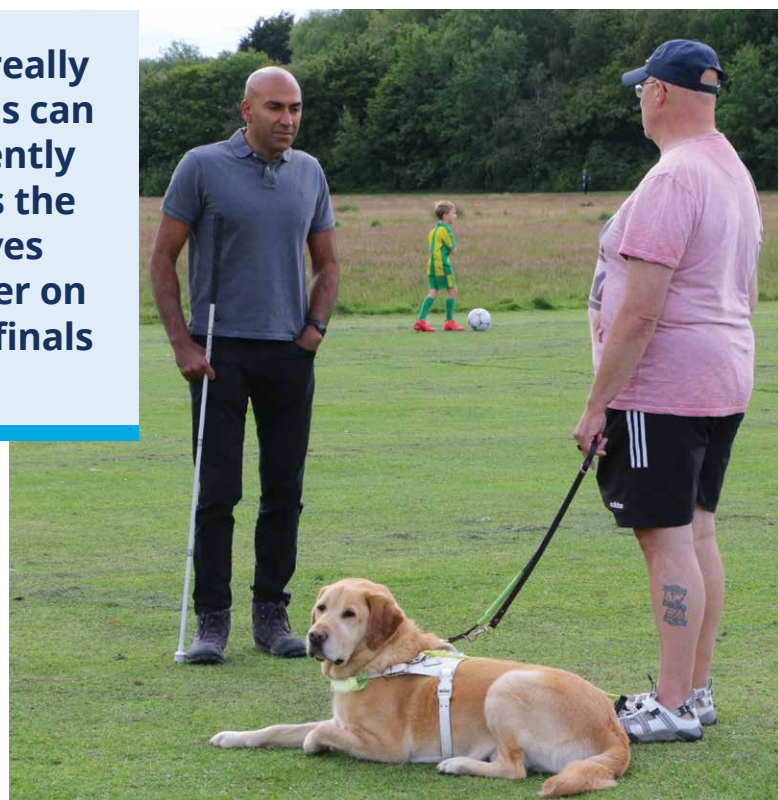
We caught up with Amar recently to find out more about how it all started and what his plans are for the future.

## How did you get into presenting?

I'd made a bit of a name for myself at BT as a blind accountant. A few of the innovations I'd developed as part of their finance division had made quite a splash, so one day I got an email from someone at the BBC asking me to trek across Nicaragua for *Beyond Boundaries*. I practically bit their hand off! Aside from the amazing travel opportunity, I'd been looking for a way to get the word out about my fledgling little tour company, and what better way to do that than hike through a jungle on national television?

## Who inspires you and why?

My father – over the course of his life he went from selling soap as a barefooted youth in Pakistan to a successful businessman in Glasgow. Not only that, but he did it all whilst supporting his wife and five children (three of whom were blind) and



creating an environment for us that inspired us all to get out there and do as well as he did!

## Where would you like to go that you haven't been to yet?

This might be a bit of a surprise, but I've never been to Cornwall! Everyone tells me how lovely it is, so it's definitely on my bucket list – it's just really strange that I've spent the last 15 years leading blind and sighted folks all over the world, and yet still haven't visited this little corner of home!

## Do you use technology to support you in everyday life?

Absolutely! I always say that technology is the number one liberator for disabled people. My number one most useful

# and fulfilment in the world'

bit of tech is my iPhone – Apple have always led the field when it comes to accessible technology, and their stuff is just so easy for me to use. They build accessibility right into the heart of the product, rather than bolting it on like an afterthought.

On top of that, there's plenty of amazing apps available for it, like BeMyEyes ([www.bemyeyes.com](http://www.bemyeyes.com)), which helps you get sighted assistance from a volunteer at any time. Another favourite is SeeingAI ([www.microsoft.com/en-us/ai/seeing-ai](http://www.microsoft.com/en-us/ai/seeing-ai)), particularly its face-recognition setting – it's almost spooky how good it is at guessing your age!

## **Do you keep up to date with the latest research into retinitis pigmentosa?**

I always get a warm feeling from knowing that there are wonderful organisations out there like Retina UK – people who are working away tirelessly to support research for a cure. However, since I was young I've learned not to get too excited by media or news stories about potential cures. It's meant that I can be really satisfied with my life as it is, and has allowed me to realise that, despite being blind, I can still find so much happiness and fulfilment in the world.

## **Do you think that the pandemic has had an impact on your mental health?**

The pandemic has been a very scary

time, and especially for us blind folks. The isolation that came from not being able to get out and contact others really took its toll.

More recently, though, things have been taking a bit of a turn for the better. For example, thanks to social distancing, I had to come up with a way for my friends to guide me on walks without getting too close; by setting up a video call on FaceTime or WhatsApp and then sticking my phone in my runner's belt, my friends can now guide me from anywhere in the country! Even better, it's allowed me to experience the peace and quiet of nature like never before – all they have to do is guide me out to somewhere in the countryside and then hang up and leave me to it. It's actually been quite liberating!

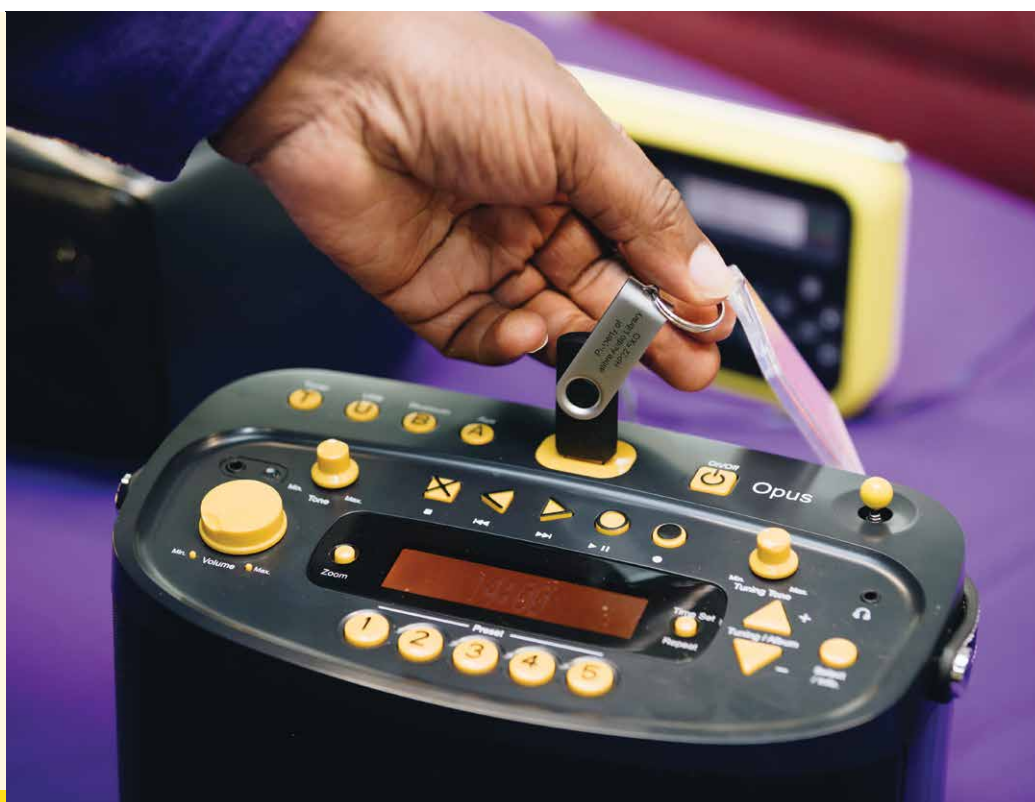
## **Celebrity MasterChef was a great success and you have a growing fan-base. How do you feel about that?**

Honestly, more than anything I'm just so touched! Everyone's been so kind and supportive, and it's really inspiring to see all the messages people have been sending. The most encouraging thing though, is seeing all the sighted folk beginning to realise how possible it is for us blind people to actually succeed in life, and how it is that we go about living our lives independently.

You can watch the Retina UK BBC Lifeline appeal online: [www.bbc.co.uk/lifeline](http://www.bbc.co.uk/lifeline).

# Memory sticks introduced for Newsletter

Several of you have been in touch to tell us that you no longer have a CD player and that your device has a USB slot for a memory stick. We are also aware of the environmental impact of sending out CDs that are then thrown away.



Thanks to sponsorship from Janssen, we are delighted to be implementing the use of returnable memory sticks instead of CDs with this issue of Look Forward. If you prefer to receive Look Forward on CD we will continue to offer it in this format.

The memory stick will arrive in a pouch, similar to those used by Calibre Audio Library. The pouches are only available via the Articles for the Blind scheme which also allows you to return the memory stick to us (for free) when you've finished listening so that we can re-use it. We need your permission to send post to you in this way so, if we don't already have your consent, please ensure that you tell us you are happy to receive it in this way.

**Look Forward is available in the following formats:**



Print



Email (PDF and Word)



Audio CD



Audio memory stick



Braille

If you would like to update your preferences and receive the next edition of Look Forward in a different format, please complete the form on our website [www.RetinaUK.org.uk/look-forward](http://www.RetinaUK.org.uk/look-forward), email us at [info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk) or phone 01280 821334.

# Big Give Christmas Challenge 2020

One donation, twice the impact

**The Big Give Christmas Challenge is back! We're aiming to raise more than ever to support ground-breaking medical research at this crucial time.**



The COVID-19 pandemic has created significant challenges for the research community. Laboratories closed temporarily during lockdown, and some teams were forced to destroy materials they had been working on for months, unable to provide the daily maintenance they required.

Now is the time to kick-start medical research once again, helping researchers to regain lost momentum and drive progress towards effective treatments for families affected by inherited sight loss. To make this possible, **we've joined this year's Big Give Christmas Challenge and set ourselves an ambitious target of £40,000!**

From midday on 1 December until midday on 8 December donations made online via the **Big Give Christmas Challenge** website will be **doubled** from a match funding pot of £20,000 provided by generous funders. This is your opportunity to make **one donation and have twice the impact** on pioneering research.

**Save this page, or put a note in your diary for midday on 1 December to make your contribution go twice as far.** You can find out more about how the challenge works, and a link to the Big Give Christmas Challenge website on our website: [www.RetinaUK.org.uk/BigGive](http://www.RetinaUK.org.uk/BigGive).

**Remember, only donations made on the Big Give Christmas Challenge website between midday on 1 December and midday on 8 December (whilst the match funding pot lasts) are eligible to be doubled.**

**Any Questions?** Call Deborah on 07841 004565 or email [deborah.laing@RetinaUK.org.uk](mailto:deborah.laing@RetinaUK.org.uk).



# New mechanism discovered for retinal

**Led by Professor Alison Hardcastle at UCL Institute of Ophthalmology and her collaborator Dr Susanne Roosing at RadboudUMC in The Netherlands, the researchers have identified a new cause of retinitis pigmentosa (RP) in 22 families with over 300 affected individuals. These include members of the first ever family affected by an inherited retinal condition to have their family tree drawn up at Moorfields Eye Hospital over 35 years ago, whose underlying genetic fault remained a mystery until now.**

The research was made possible by Retina UK as the major funder of the UK Inherited Retinal Dystrophy Consortium (UKIRDC), with partner funding from Fight for Sight.

In a landmark paper published in The American Journal of Human Genetics, the researchers pinpoint the DNA alterations that cause the condition in these families. Professor Alison Hardcastle said: "It was a challenge to identify the DNA alterations causing this form of retinitis pigmentosa. Most other changes identified as the cause of retinal diseases affect the sequence (*'spelling'*) of a particular gene. In these 22 families we did not find gene changes, instead we identified complex re-arrangements of chromosome 17."



Chromosomes are long threads of DNA; in humans, all of our 25,000 or so genes are arranged in a particular sequence within 23 pairs of chromosomes, which are found in nearly every cell in our bodies. While the genes themselves provide instructions for building proteins, there are also sections of DNA in between the genes, which control whether or not certain genetic instructions should be used in a particular type of cell. For example,



# damage in retinitis pigmentosa

retinal cells don't need proteins that only do a job in the intestine. For Prof Hardcastle and her team, the next challenge was to investigate how re-arrangements of all this genetic information in chromosome number 17 might lead to retinal degeneration.

The researchers used skin-derived stem cells from people living with this type of RP and, through a painstaking process, turned them into a 'retina in dish' to model the condition. They found that the three dimensional structure of chromosome 17 was altered so that a gene called GPD1 inappropriately made contact with a molecular 'on' switch for expression in the retina. This means that the protein production process in retinal cells 'reads' the GPD1 genetic instructions when they should be ignored, and we can guess that the resulting GPD1 protein might exert a damaging effect on the eye.

*"Finding a cause, let alone a cure, seemed almost impossible when I was first diagnosed with retinitis pigmentosa over 30 years ago."*

*Sue Perkins*

Professor Hardcastle said: "This represents a new mechanism of retinal disease, and new understanding of how alterations of the human genome can cause inherited conditions. We hope our

discovery and new knowledge will now lead to many more similar discoveries."

Sue Perkins is a member of the family involved in the study. She said: "Finding a cause, let alone a cure, seemed almost impossible when I was first diagnosed with retinitis pigmentosa over 30 years ago.

"We got involved in the search some four and a half years ago now, when we contributed some DNA samples from family members. Later, a couple of skin stem cell samples were used to grow retinal cells in the lab. This was very exciting and something quite new. We waited patiently and eventually news came that something a bit unusual had been discovered.

"I hope this work will not only help us in the future, but also other family groups with similar conditions. It has been a privilege to have a glimpse at this pioneering work."

The team's breakthrough in understanding the genetic basis for this type of RP means that researchers can start developing potential treatments to slow disease progression and preserve vision.

**Thank you so much for your generous support, which enabled Retina UK to help make this amazing progress possible.**

# 'Every screaming second

**All of our amazing fundraisers are superheroes to us. They work tirelessly to raise money so people with inherited sight loss can get the information and support they need today and we can search for treatments for the future. We are incredibly grateful to each and every one of them.**

Whether you run a marathon, organise a bake sale or host a quiz (to name but a few different fundraising ideas), it's your fundraising that makes our medical research and support services possible.

James Clarke (25) has been raising money for Retina UK for the past four years. He was diagnosed with retinitis pigmentosa and registered partially sighted at the age of 20. He is incredibly upbeat and optimistic and the money he has raised so far has had a positive impact on the work we fund, as well as on his own sight loss journey.

James currently works as an events planner as well as helping friends arrange parties, organising several large charity events and other celebrations. He uses those same skills to organise the fantastically successful Worksop's Got Talent (sadly postponed in 2020 because of the pandemic but due to return in November 2021). The last time it was held, he welcomed

more than 700 people to the event which was judged by a celebrity panel. Previous celebrities have included Corrie's Kym Marsh, Grammy winner Eliot Kennedy, Love Island stars and many more. To date the show has raised over £37,200 for Retina UK.

He describes event organisation (which many of us would feel daunted by) as "fun" and said: "Organising a show for a charity that you care so deeply about spurs you on and I love the sense of achievement when I stand there and see hundreds of people enjoying something that I have worked on. I can't recommend fundraising enough and the support that Retina UK provides towards the events is invaluable". He has played to his strengths in event organisation to raise money, but enjoying yourself along the way is so incredibly important.

In September 2020 James completed a skydive for Retina UK which he describes as a "once in a lifetime" experience. His employer, law firm Irwin Mitchell, offered match funding which boosted his total up to £2,300. Match funding is something which many employers offer – it's always worth asking the question if you are fundraising. Speaking about the skydive, James said: "Once the total kept rising and rising, it motivated me more than ever to do something crazy to raise as much money as

# was worth it'



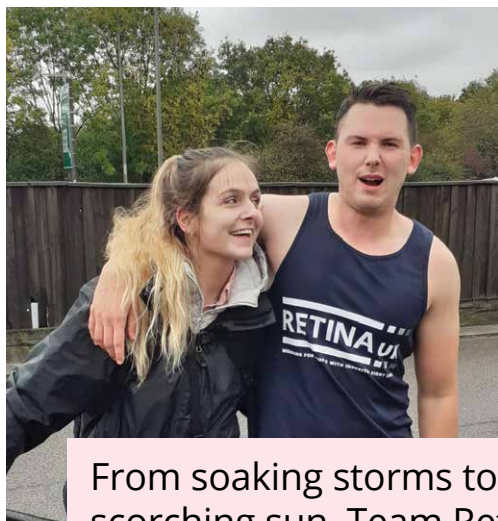
possible in this year where charities have been hardest hit. It was the scariest experience, but once I was out, I started to enjoy the indescribable sensation! To raise a further £2,300 for Retina UK made every screaming second worth it! Doing something crazy is a unique selling point and I was lucky that so many people got behind it, invested in it and sponsored me."

## Take on a skydive for Retina UK

- Tandem skydive
- 10,000 ft, fall at 120mph
- 21 locations across the UK with Skyline
- Raise at least £395 sponsorship
- Dedicated support from our fundraising team throughout.
- Find out more:  
[www.RetinaUK.org.uk/skydive](http://www.RetinaUK.org.uk/skydive)



# THANK YOU



From soaking storms to scorching sun, Team Retina UK braved the weather and each took on 26.2 miles to complete The 40th Race! Thank you to Alan, Amelia, David, Eve, Frances, James, Jonathon, Julie and Michelle who raised over £4,500 through this virtual marathon.



We are extremely grateful to have received £25,000 from the Lloyd's Market Charity Awards. Thank you to the Lloyd's Charities Trust and to all of our supporters working in the Lloyd's Market who nominated Retina UK!



Dave took on the coast to coast route from Whitehaven to Cumbria on two wheels! With support from family and friends, he raised an incredible £1,170!

We love to hear about all of the great fundraising that goes on up and down the

Sophie soared into the sky strapped to a 1940's biplane and took on a wing walk, raising an amazing £1,328! Sophie chose to support Retina UK as she lives with Usher syndrome.



Retina UK staff have entered into a sweepstake for the winner of the Great British Bake Off raising £40 in the process.



Pauline hosted a virtual quiz for the wider Graham family – "It was a really good way to see one another and was a close fought competition. We were delighted to raise £686!"



Finally, thank you to Iris (9) who donated her £5 prize to Retina UK after coming second in a competition run by Buckingham Fringe Week 2020.





# It's good to talk

**HELPLINE:**  
**0300 111 4000**

Available Monday to Friday  
9.30am to 9.30pm, or you can  
email [helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk)



**Our Talk and Support service matches those who would like a regular phone conversation with a friendly volunteer who is affected by inherited sight loss.**

The service is open to all those aged over 18 who live with inherited sight loss as well as family members.

Talk and Support offers a social link on a more personal and longer term basis than our helpline, with regular calls being made for as long as they are beneficial.

*"I've never spoken to anyone else with my condition before and I found it so helpful just knowing I'm not alone!"*

Conversations don't need to centre on sight loss; practical information, hints, tips and encouragement about living with progressive sight loss are often discussed. It may be that people choose to have a general chat and talk about everything from their families and daily life to current affairs and interests – it's entirely up to those who use the service to choose.

The service is confidential (except for any safeguarding concerns), calls

are not discussed with anyone and no record is kept of the content of conversations. Those who use the service can decide when to stop the arrangement.

Our volunteers are good listeners, trained and are all either directly affected by inherited sight loss or have a close relative who is.

If you would welcome a friendly phone call once or twice a month from one of the team, or you know someone who would, please contact the Retina UK office on 01280 821334 or by email on [services@RetinaUK.org.uk](mailto:services@RetinaUK.org.uk).

*"I was at an extremely low ebb when I rang and a lady spoke to me over the course of several weeks. We had a break and then resumed to find out how I was going on. I am certain without that support I would not have got through that horrible time and her words stay with me to help me through today. It is an absolutely brilliant and well needed service. I thank Retina UK with all my heart."*

*Jan – now training to be a volunteer on our Helpline and Talk and Support service.*



## Pick the right format for you

Did you know that we produce this newsletter, Look Forward, in a variety of different formats. You can choose from:

- Print (postage paid and Articles for the Blind scheme)
- Digital (Word and PDF)
- Audio (CD and memory stick)
- Braille

If you'd like to change the format you receive, just email [info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk) or complete the form at [www.RetinaUK.org.uk/look-forward](http://www.RetinaUK.org.uk/look-forward). If you would like to receive Look Forward by memory stick, we do need your permission to send it to you via the Articles for the Blind scheme.

## The Retina UK Podcast

Our plans for 2021 include a regular Retina UK Podcast with a variety of guest speakers talking about research, fundraising activity, information and support, events and volunteering opportunities.

Our Research Development Manager, Kate Arkell recently interviewed Professor 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 on our website: [www.RetinaUK.org.uk/recordings](http://www.RetinaUK.org.uk/recordings).

Our Podcast is available on Breaker, Apple Podcasts, Google Podcasts, Overcast, Pocket Casts, Podbean, RadioPublic and Spotify.

## Archive audio content

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: [www.anchor.fm/retina-uk](http://www.anchor.fm/retina-uk).

# Cash prizes to be won

This year's Retina UK Christmas Raffle is bigger and better than ever. If you've not received your tickets in the post you can request them on our website: [www.RetinaUK.org.uk/raffle](http://www.RetinaUK.org.uk/raffle), by calling Deborah on 07841 004564 or by emailing [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk).

By entering, you will be in with a chance of winning one of these brilliant prizes, just in time for Christmas!

**1st Prize – £500 cash**

**2nd Prizes (five) – £100 cash**

**3rd Prize – Luxury Christmas Hamper**

**4th Prize – £40 One4All Gift Card**

**5th Prize – Amazon Echo Dot**

The deadline for returning your ticket counterfoils is Wednesday 9 December 2020 and the draw will take place on Friday 11 December 2020. We'll let you know if one of your tickets is a winner!

Your support is so important during these challenging times, and your contributions will help to fund vital services for our community, as well as ground-breaking research into inherited sight loss.



## Have you received your tickets?



# COVID-19: Keeping retina re

**As the UK locked down in March, most researchers had to switch off their equipment and lock the laboratory door behind them, leaving petri dishes and lab benches to gather dust over the next few months. Scientists funded by Retina UK were no exception; many were midway through projects that had been making excellent progress. Although they carried on analysing data and writing papers at home, their experimental work was severely disrupted.**

## Months of work lost

Professor Majlinda Lako at Newcastle University had been investigating an RP gene called PRPF31. This gene normally provides instructions for making a protein which is part of the machinery used by cells to edit out unwanted sections of genetic code.

Problems with PRPF31 create a variety of knock-on effects, and Professor Lako's team were making great progress in understanding the consequences of defects in the gene editing process for the retina. They had pinpointed a particular layer of retinal tissue and identified various avenues for further investigation, as well as potential targets for future treatments.

However, the team's key tools for this work were special living 'models' of retinal tissue, painstakingly grown over several months from the skin cells of people with PRPF31 mutations. When lockdown happened, the researchers were forced to vacate their lab at short notice and, with no way of preserving

these models, had to discard them, losing valuable work.

We will be providing Professor Lako with some extra funds to recreate the models and get the project back on track. The University has promised ongoing lab access in the event of another lockdown.

## Retaining talent

Meanwhile, over in The Netherlands, another Retina UK-supported project was hit with delays.



# search on track



Professor Frans Cremers at Radboud University is working on Stargardt disease. With funding from Retina UK, his team had already made several important discoveries of previously 'hidden' faults in the gene most commonly associated with Stargardt's, explaining the underlying cause of a large number of cases. This had enabled the team to move on to investigating whether the faults could be patched over as a possible approach to treatment. However, they were forced out of the lab in spring.

As is often the case, talented PhD students and junior researchers were the linchpins of the project, completing most of the day-to-day lab work, but their salaries are usually paid for through fixed term grants and contracts.

Retina UK has agreed to extend the time period for our grant payments, while Professor Cremers has juggled some funding to save costs. This has enabled promising young scientists to stay on this project and see it through to completion.

These are just two examples of the effects of the pandemic on our current research projects, all of which have been affected to some degree. We are determined to continue to support our fantastic researchers as they get things back up and running, so that they can make the breakthroughs our community needs. We can only do this with your help; we need your support more than ever.

You can make twice the impact if you donate between midday on 1 December and midday on 8 December through the Big Give Christmas Challenge. Donations are matched so that a £10 donation is worth £20 to us during the Big Give week. Find out more at [www.RetinaUK.org.uk/BigGive](http://www.RetinaUK.org.uk/BigGive).

# Positive feedback from online local groups

**It has been quite a while since any of our local groups have been able to meet and so in September we supported three pilot online meetings in London, Somerset and Scotland. We are all too aware of the mental health challenges that lockdown has presented and it has never been more important for people to connect, albeit in a socially distanced way.**

Restrictions have meant that we have had to look into new ways of bringing people together safely. Zoom has proved enormously useful and accessible to our community with people able to join in whichever way worked best for them (e.g. phone, smart phone, tablet, laptop or desktop computer). We were also able to offer personalised support in advance of the meetings to anyone who was unfamiliar with this technology.

Our Research Development Manager, Kate Arkell, gave a very interesting research update at two of the

*"I joined by phone and it was well worthwhile. I think this style of meeting should be tried again as it provides an excellent way for people to keep up to date without having a difficult time travelling to a physical location."*  
Prof Clif

meetings. We plan to make this content available on our Podcast channel in the future ([www.anchor.fm/retina-uk](https://www.anchor.fm/retina-uk)). At the London meeting Professor Andrew Webster talked about the new MyEyeSite app which aims to give people living with rare eye conditions ownership of their own digital medical data. You can find out more on our Podcast channel or by visiting [www.myeyesite.health](https://www.myeyesite.health).

Feedback has been overwhelmingly positive so far with a real appetite for future and more regular meetings being held in this way.

*"Thanks for suggesting and organising last Tuesday's Zoom meeting. I found it really helpful to have a chat with folk. Kate's talk was also very interesting - please pass on my thanks to her too. Also thanks to Matt for chairing it and keeping us in order!"*  
Valerie

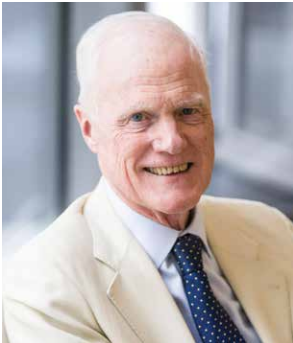
The next scheduled meeting is London on Saturday 21 November.

## Interested...

If you are interested in taking part in a local group or indeed hosting one yourself, please contact Jacqui on 07841 486008 or email [services@RetinaUK.org.uk](mailto:services@RetinaUK.org.uk).



# Chairman's update



You may recall that in the last Look Forward I noted that when we started 2020, it was with great expectations. We had ended the previous

year in good shape and had bold, achievable plans to grow our income significantly and widen the scope of the research and support we fund. Then the coronavirus arrived and had an extraordinary effect on all our lives. Well the good news is that the charity is today in robust good health. Prudent management, legacy work years ago and the sheer drive to make things work has brought us through. Our fundraisers have successfully scoured every opportunity to get financial help. One highlight was that the BBC Appeal, fronted brilliantly by Amar Latif, raised a miraculous £35,000 and, even more importantly, gained awareness nationally of inherited sight loss.

The research labs that had closed have largely re-opened. There has been some unavoidable (and expensive) loss of important cultures which were 'cooking' nicely when shutdown arrived. Do read Kate Arkell's article on all this (pages 18-19). You can help enormously by donating to the Big Give – a super way for your donation to double!

As you are reading this, you probably know that our Trustee Board is a

pretty special group of people bringing different skills to the oversight of the charity. One thing they have in common is that they are all devoted to making Retina UK as successful as possible. It has been my privilege to be the chairman for the past nine years. Built into our constitution is the recognition that the charity needs to refresh its Board in an orderly way. I was due to step down at the September 2020 AGM which, as mentioned elsewhere, is delayed to next spring. More vacancies are coming up and so we are recruiting for other new Board members. What do candidates need to know? First, that ours is a special charity with a well-established volunteer ethos and that the outlook is very positive – bold targets for fundraising to support the best research and to help our community. Next, that Trustees must be prepared to attend meetings throughout the year – usually quarterly in London but currently more frequently using Zoom - and to contribute relevant skills and time to make Retina UK stronger and even more effective.

If you are interested in putting your name forward or know someone else you think would be a good Trustee, register interest by emailing [trusteeapplications@RetinaUK.org.uk](mailto:trusteeapplications@RetinaUK.org.uk). The posts are unremunerated and no previous Trustee experience is required.

*Don Grocott*

# Leave a lasting legacy



To request a copy  
of our legacy leaflet  
please contact  
[alice.capper@  
RetinaUK.org.uk](mailto:alice.capper@RetinaUK.org.uk)



**We are so grateful to everyone who chooses to remember Retina UK in their Will. Gifts in Wills are an incredibly special way to show your support and help ensure we can continue funding vital research and supporting people affected by inherited sight loss for years to come.**

Joseph Dunn passed away in 2019 and left a generous gift in his Will to Retina UK. His brother John and sister-in-law Alison told us about Joe and his decision to leave a legacy:

"Joe was born in 1934 in County Durham. Neither of our parents nor our siblings had any issues with their own eyesight, and it wasn't until the 1970s that Joe was diagnosed with retinitis pigmentosa.

"I recall Joe telling me that on one routine visit to the hospital, the Consultant, on discovering Joe had RP, asked if he could take a look at his eyes, as the doctor had never come across a person with RP during his career. Joe happily obliged, and eventually went on to become the 'guinea-pig' pseudo patient for the medical students as part of their practical exams.

"Joe loved his job at the Council, overseeing parks and picnic sites. It was a sad day when eyesight issues

meant he was no longer safe to drive, but the Council redeployed him to their Planning Department, where he would accompany the surveyors out into the field. Uneven ground and rabbit holes sometimes made the job unsafe, but Joe always saw the humour in the tumbles he took.

"In his home life, Joe adored fishing, growing prize-winning chrysanthemums and listening to classical music. Joe was very interested in stem cell research, and he and his wife Jean attended talks on the subject. It was therefore a natural progression in deciding that charities such as Retina UK should be supported both before and following his death. Although a keen supporter of Guide Dogs for the Blind, Joe felt that smaller charities always find themselves in direct competition with the larger, household names, and are often overlooked. Consequently, he decided to leave bequests to Retina UK and Calibre Audio Library, both of which had meant a great deal to him."

If you would like more information about remembering Retina UK in your Will, or would like to tell us about your decision to leave a gift (this is not a requirement, but we'd like to say thank you), please contact: Alice Capper, Trusts and Major Gifts Officer, on [alice.capper@RetinaUK.org.uk](mailto:alice.capper@RetinaUK.org.uk). Alternatively you can find more information on our website: [www.RetinaUK.org.uk/legacy](http://www.RetinaUK.org.uk/legacy).



# We are so grateful for all donations to our work



Please make your selections below and post the form back to Retina UK, Wharf House, Stratford Road, Buckingham, MK18 1TD, or, if you prefer, call 01280 821334 or donate online at [www.RetinaUK.org.uk/donate](http://www.RetinaUK.org.uk/donate). Thank you.

☐ I enclose my cheque for £\_\_\_\_\_ payable to Retina UK.

☐ I would like to make my donation of £\_\_\_\_\_ by debit/credit card.

Card Holder Name: \_\_\_\_\_

Card Type: Mastercard ☐ Visa ☐ Maestro ☐ Delta ☐

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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Start Date:   Expiry Date:   Issue Number (Switch only):

Last three numbers on the reverse of the card:

If you would like to set up a Direct Debit, please visit our website [www.RetinaUK.org.uk](http://www.RetinaUK.org.uk) or call the office on 01280 821334.

## Contact details

Title: Mr/Mrs/Miss/Other (please specify) \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_ Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

☐ If you would like to receive information from us via email please tick this box (This will include general updates and information about support services, events, research, fundraising and surveys. You can opt out of some or all communications, or amend your preferences by calling us on 01280 821334 or emailing [info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk))

If you gift aid your donation, the charity will receive an extra 25p for every £1 that you give!

☐ I confirm that I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts in that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand that the charity will reclaim 25p of tax on every £1 that I give.

Signature: \_\_\_\_\_

Start date: \_\_\_\_\_