

# LOOK FORWARD

With spring just around the corner and the vaccine roll-out moving along apace, inside we look forward with optimism to the year ahead. We may need to do things differently, but there are many ways to get involved including by attending our online conferences (page 8) and fundraising closer to home to support our work (page 18).

# Welcome to Spring



Times are still tough as the pandemic disrupts our day-to-day life, but I am determined to be cautiously optimistic about the opportunities that 2021 will provide, on a professional level on behalf of Retina

UK and our amazing community and on a personal level with my family and friends. With spring just around the corner, maybe now is the time to enjoy the outdoors and try your hand at gardening. You'll find some hints and tips in our article on pages 22-23.

Our Annual Conference (pages 8-9) is going to be very different this year because it will be held online. The up-side of that is that we hope that many more people will be able to join us because there is no need to travel – you can even tune-in wearing your pyjamas – we won't judge you! We've got a fantastic line-up of speakers and we'll be launching our new 'Unlock Genetics' website. Don't miss it and register now

at [www.RetinaUK.org.uk/annual-conference](http://www.RetinaUK.org.uk/annual-conference).

Our fundraising for 2020 ended on a real high, with more than £45,000 raised through the Big Give Christmas Challenge. This is the most we've ever raised from this appeal – a real achievement which will help the scientific community regain momentum in our search for potential treatments. You'll see some exciting suggestions to kick-off 2021 fundraising on pages 18-19. We hugely appreciate all of the support you give us and the feedback we get is that you really do get a lot from participating. The team is here to support you and make sure you have a really positive experience, so please do get involved.

As always, if you have any thoughts to share about our charity, please email me at [chiefexec@RetinaUK.org.uk](mailto:chiefexec@RetinaUK.org.uk). I really value your ideas and feedback.

*Tina Houlihan, Chief Executive*

---

**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)

---



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



# Join the Retina UK panel

Knowing a bit more about you helps us to offer you opportunities and events by area, sight loss condition and even specific to your genetic diagnosis.



You can also choose to become part of the Retina UK panel, which will enable us to contact you about opportunities to become involved in research studies, in-depth surveys and be a voice for the sight loss community.

These are some of the activities our Retina UK panel have been involved in:

- Patient advisory committees for two pharmaceutical companies (these opportunities were condition / gene specific); the companies rely on these committees to ensure that their work is meeting the needs of the inherited sight loss community.
- Interviews for a study of the attitudes of people living with inherited conditions towards gene editing therapies.
- An online study about sound

- perception in people with sight loss.
- Questionnaires for the IRD COUNTS consortium study on the economic and wellbeing impacts of inherited sight loss. The results of this will be used in campaigns to enable access to new treatments.

If you would like to hear about how you can get involved, please complete the form on our website: [www.RetinaUK.org.uk/more-info](http://www.RetinaUK.org.uk/more-info) or email us at [info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk).

Your email address is key for notifying you about these opportunities because they are usually communicated electronically as they often have short deadlines; *Look Forward* is produced three times a year and we send an e-Newsletter once a month.

# From small beginnings...

**We recently took a trip down memory lane with our founder and Honorary President, Lynda Cantor, who is still actively involved in our work. The full interview is now available on our podcast channel [www.anchor.fm/retina-uk](http://www.anchor.fm/retina-uk).**

Lynda founded Retina UK (formerly the British Retinitis Pigmentosa Society and RP Fighting Blindness) in 1975 after being told she had retinitis pigmentosa (RP) and that there was nothing that could be done. There was no information, no support network, no research into the condition and no treatment. It led her to America to see an ophthalmologist who introduced her to Ben Berman who had founded the Retinitis Pigmentosa Foundation in America. He was keen that she get a similar organisation going in the UK.

At the time, Lynda had two small children and no experience of running a charity, but she thought she'd give it a go. She had 15 names of British people who had contacted Ben and she wrote to them to say that she was thinking about getting an organisation together in the UK. They were incredibly enthusiastic and supportive. After a Sunday afternoon appearance on BBC Radio Four 'In Touch' she received a deluge of 500 letters. And that's where it all began...



When the charity first started, it was totally volunteer-led. At the very first AGM people offered to start branches in different areas of the country and friends helped by typing letters and looking after her children. Lynda explained: "We had the idea to start a helpline which was easier said than done without the technology we have today. We bought an answerphone

and added a message 'your helpline operator is ....'. A team of volunteers each took responsibility for the helpline for one evening from 6.00pm – 10.00pm. As technology advanced we changed the system to BT who just transferred the calls to whoever was on duty. It only fell down when the person who was on duty that night forgot! We had some laughs."

Lynda continued to be the driving force behind the development of the charity and was also involved in the setting up of Retina International. She describes her proudest moment as when she was awarded an MBE in 1994. She said: "I felt I was receiving it on behalf of all of our members and what we had achieved. I met the right people at the right times and we struck lucky sometimes."

The charity has invested £16.5 million into research to-date. Lynda's first fundraising event, a party in her garden, raised £189. She said "I thought it was an enormous amount of money at the time."

As far as the future is concerned, Lynda is optimistic about the possibility of treatments for inherited retinal dystrophies. Her advice is "Be patient. Treatments are coming slowly and nothing happens overnight. Almost 50 years since starting the charity I didn't think we would ever have a cure; but

we will. Absolutely we will find it."

Lynda believes the most important step towards finding successful treatments is to identify all of the genes which contribute to inherited retinal dystrophies.

We spoke to Lynda at the start of February, whilst the UK was in the grip of a third lockdown. We asked her how she has kept in touch with family and friends and what she does to support her wellbeing and mental health during this very difficult period. She explained: "Routine is very important. Get up, get dressed and have a list of things you want to achieve that day. I try to phone one or two friends for a chat, I read a lot, listen to music and listen to the television using the audio described commentary. But I haven't seen my son for a year and my daughter and I can only have a 'doorstep drop-off' as we call it. It's better than nothing."

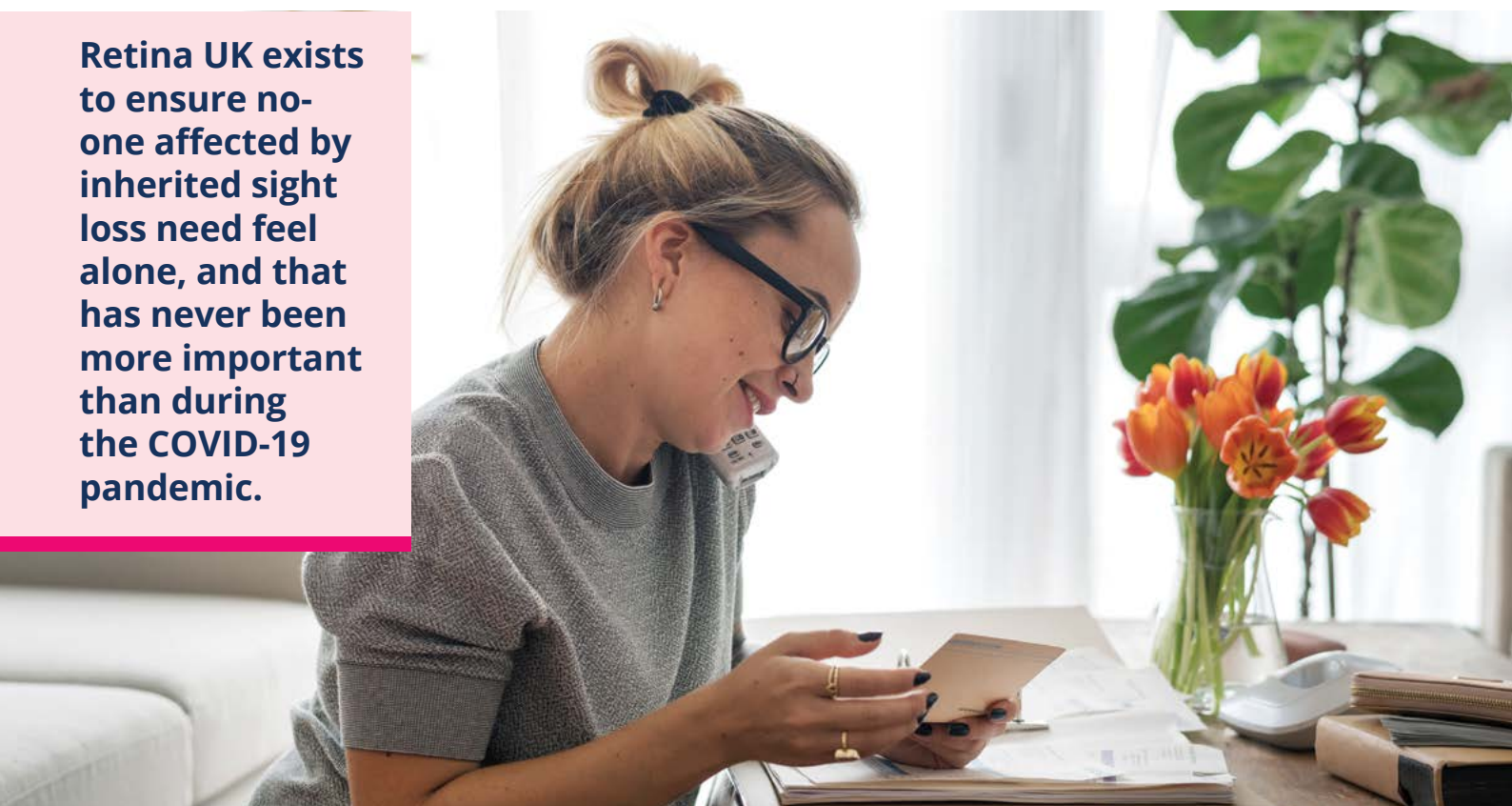
"Things will get better. Try not to be impatient, like I am. Have faith it's coming slowly. Be kind and support each other."

Lynda's book "My Vision of Hope – A remarkable story", published in 2006, is available in audio format on our podcast channel <http://bit.ly/3aUPODD>



# Helpline – We're here for you

**Retina UK exists to ensure no-one affected by inherited sight loss need feel alone, and that has never been more important than during the COVID-19 pandemic.**



Not surprisingly many people, including those in our community, have felt lonely and isolated during recent months as our opportunities to connect with others socially or through work have been severely restricted.

Thankfully, many who are struggling have reached out to our helpline and talk and support volunteers who are at the end of the phone, or an email, ready to provide a listening ear and emotional or practical support.

In 2020 we recorded a significant increase in demand for our information and support services with more people turning to our charity for support than ever before.

This included an overall rise of 23% in the number of phone calls to our helpline in 2020 compared to 2019. Between October to December 2020 we saw a 68.7% increase in helpline calls compared to the same period the previous year.

Information and Support Manager, Denise Rawden, explained that the charity has also seen a change in the type of calls.

“Early in the pandemic our community turned to us for information on how to access practical support, for example online shopping and the collection of prescriptions. We were able to provide information on services available and

to signpost to sources of help and support.

“But in recent months we’ve experienced a real change. While we are still responding to requests for practical information, a growing number of callers are telling us they are struggling with feelings of loneliness or isolation which is having a real impact on their wellbeing and mental health. The average length of a call has doubled.”

Thanks to our volunteers, all of whom are affected by inherited sight loss, we have been, and will continue to be, here to make a positive difference for everyone who turns to us for support.

*“I live on my own and most of the time that’s OK, I like it, but through lockdown there are times, you know, that I feel lonely. I have those days, the stress of everything that’s going on, but this has been really helpful speaking to you. I will call again, thank you.”*

Denise added: “I would encourage anyone who is looking for support to pick up the phone or drop us an email. We are here for you. Many callers tell us they feel much better after talking things through and sharing their thoughts or worries. We are also able to offer our talk and support service to those who would like regular contact, and make referrals to counselling services for those who we feel would

benefit from speaking with a trained professional.”

### Supporting our volunteers

We are very fortunate to have a committed group of volunteers on our helpline telephone and email service and we take their wellbeing seriously. In 2020 we secured grant funding to develop new bespoke training modules, in a number of accessible formats, to help our volunteers to protect their own wellbeing and mental health while supporting others with inherited sight loss.

The three 30-minute modules cover managing wellbeing, managing mental health and a number of useful ‘tools’. Our volunteers will use their growing knowledge in this area to enhance the support they can provide to callers. In addition to the regular supervision sessions we have also introduced new bi-monthly buddy groups to enable our volunteers to ‘check in’ with each other and provide peer-to-peer support.

### We are here for you

If you are looking for practical information, emotional support, or would simply like to have a chat, our volunteers are at the end of the phone or an email. Calls to our helpline cost the same as a local call. The service is available from 9.30am to 9.30pm, Monday to Friday – 0300 111 4000 email [helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk).

# Register now for Conferences

**They may be a little later than originally planned, but we're almost there! Our Professionals' and Annual Conferences will be held online in April and registration is now open.**

## Professionals' Conference

**Friday 16 April 10.00am - 1.30pm**

Our Professionals' Conference builds upon the success of the inaugural event in 2019, and will be held on Friday 16 April. It will start at 10.00am and finish at 1.30pm.

This Conference is aimed at professionals working with people affected by Inherited Retinal Dystrophies and their families. The last conference attracted a range of professionals including Eye Clinic Liaison Officers, Rehabilitation Officers for Visual Impairment, Qualified Teachers of the Visually Impaired, Ophthalmic Nurses and third sector professionals.

There are two key themes to this year's event, Genetics and Mental Health. We have a range of speakers including:

- Dr Panagiotis Sergouniotis who will speak about the clinical importance of genetic testing and research
- Dr Ian McCubbin, a Clinical Psychologist, who will discuss helping your clients with mental health challenges
- Professor James Bainbridge, who will be joined by one of the first patients



to receive the Luxturna treatment

- The Retina UK team, who will be launching our new and exciting Unlock Genetics website.

Registration is open for this free to attend conference. Please complete the form on our website at [www.RetinaUK.org.uk/prof-conf](http://www.RetinaUK.org.uk/prof-conf).

## Annual Conference and AGM

**Saturday 17 April 10.00am - 2.45pm**

We have a number of firsts lined up for our Annual Conference and AGM this year, starting with it being held online.

Registration is now open, please visit [www.RetinaUK.org.uk/annual-conference](http://www.RetinaUK.org.uk/annual-conference) and complete the form, or call the office on 01280 821334. As with our previous events, we have an exciting line-up of speakers including:

- Professor Alison Hardcastle, who will be giving us a run-down of the latest





genetics research and information about genetic counselling and what it means for you

- Dr Sam Da Silva, who will tell us about the latest in clinical research
- The Retina UK team, who will be launching our new Unlock Genetics website.

This year we will welcome representatives from the pharmaceutical industry who will give presentations on some of their cutting-edge work to find treatments. Following the conference we will hold our Annual General Meeting (see page 15).

**We look forward to seeing you all at the conferences!**

**If you have any questions or concerns about how to join these meetings we will be happy to help. Please call us on 01280 821334.**

## Getting together 'virtually'

While our local peer support groups can't meet face-to-face, many are enjoying meeting online and by phone.

We have welcomed some interesting speakers who have shared information about the new Moorfields Oriel project; MyEyeSite; research and much more.

We are planning meetings for Scotland, London, Somerset, Birmingham, Oxford, Manchester and Kent in the next few months. We would love you to join us.

Details of upcoming meetings will be published on our website: [www.RetinaUK.org.uk/peer-support](http://www.RetinaUK.org.uk/peer-support) or email [services@RetinaUK.org.uk](mailto:services@RetinaUK.org.uk) and we will keep you up-to-date. Distance need not be a barrier to attending. Do let us know if you would like support to access these meetings.

*"Thanks so much for hosting the London group meeting today! It was fantastic to come together and share experiences, now so more than ever given how the restrictions have made travelling and socialising harder."*

# What is Charles Bonnet Syndrome

Have you ever seen something that isn't really there? If so, you may be experiencing hallucinations caused by Charles Bonnet Syndrome (CBS).



Visual representation of Charles Bonnet Syndrome by Jeremy Webb [www.jeremywebbphotography.com](http://www.jeremywebbphotography.com)

This is a little-known condition, yet it is common in adults and children who have lost over 60% of sight, including those who live with inherited sight loss conditions.

Researchers who are investigating CBS have discovered it is not a mental health condition, but is in fact caused entirely by loss of sight. CBS is caused by your brain reacting to your loss of vision. It can sometimes try to fill the 'gaps'.

Even though people often realise whatever they are seeing isn't really there, it can still be frightening

## Why Charles Bonnet?

Charles Bonnet syndrome is named after a Swiss philosopher and writer who lived about 250 years ago. Charles Bonnet wrote about the experiences of his grandfather, who began seeing things that were not actually there after losing his sight following cataract surgery.

and upsetting to experience CBS hallucinations.

What people see can vary from shapes, patterns and colours to vivid images of people, animals or objects. They may move, or be still and there is no sound.

It is important you tell your doctor if you

# (CBS)?

are experiencing hallucinations so that they can rule out any other conditions. It can also occur when another medical condition such as Parkinson's disease, a stroke, or an accident affects parts of the brain that deal with sight.

There is no cure, or specific medication proven to treat CBS, but there are things you can do to help. Simply talking about what you are experiencing with others may make it easier to cope and knowing it is due to sight loss and not a mental health issue reassuring.

Elizabeth began losing her vision from retinitis pigmentosa (RP) in her childhood. She started to experience visual hallucinations in her teens which she says she found very 'unsettling' and sometimes 'terrifying'.

She explained: "I, like so many people, didn't say anything about it to anybody. I didn't know what it was, and I didn't know why the things I saw were there.

"Until my 30s I had never heard of CBS, when I did I began to work out that was possibly what it was. The hallucinations did continue from time to time over the years. When I started to ask people with various degrees of sight loss if they saw things that weren't there, an amazing number of people said 'yes'. As soon as I realised other people had experienced it I felt better. I felt more ordinary.

"It helps people to know that others

have had a similar experience. I think most people then feel better, even if it doesn't go away straight away.

"A lot of people feel there is something wrong with their mental health, or their family are even telling them there is, or rubbish the suggestion in the first place. It was very real to me and it is very real to the people I speak to."

## Information and support

If you live with an inherited sight loss condition and experience CBS, Retina UK can arrange for you to speak with someone with lived experience. Email [services@RetinaUK.org.uk](mailto:services@RetinaUK.org.uk) or phone our helpline and ask for a referral 0300 111 4000.

For online information about CBS and coping strategies, visit Esme's Umbrella:  
[www.charlesbonnetsyndrome.uk](http://www.charlesbonnetsyndrome.uk)

If you have questions about CBS and would like to learn coping strategies, contact Esme's Umbrella helpline (answered by RNIB Eye Health Team) on 020 7391 3299.

To attend a group telephone counselling service for people experiencing CBS (irrespective of sight condition),  
phone 0300 3030111.



# THANK YOU

We were grateful to secure funding from the National Lottery Community Fund to support delivery of our vital information and support services during the COVID-19 pandemic.



Miri is taking on a virtual cycle covering 1,083 miles in her local area (that's the distance from Land's End to John O'Groats!). Miri has already raised over £1,200 and as she tackles the second half of her journey we want to say a huge thank you!



Family, friends and colleagues of Laetitia have raised more than £6,500 in her memory after she sadly passed away in December. Laetitia was a long-standing supporter of the charity and took part in our tandem cycle challenge in 2019.



Catherine and her husband Gideon took on a 10-mile walk in their neighbourhood to complete our 10 for 10 Virtual Challenge. Through this they raised a fantastic £100 – thank you!

Thank you for all of the imaginative ways you've fundraised so far in 2021.



Martin, Managing Director of Euroglaze (pictured on the cover of this newsletter), and his friend Daniel embarked on a virtual January cycle challenge. Both took on 1,000km from their garages!

Euroglaze are fantastic corporate supporters, choosing Retina UK as their Charity of the Year partner in 2019, and continuing to fundraise for us. Huge thanks to Euroglaze, Martin and Daniel.

David cycled an incredible 600km in January, raising over £900! By using Zwift, David was able to cycle the streets of New York, Paris and London all from his garden. Thank you David!



We're very grateful to everyone who took part in our fundraising campaigns over the festive season. Our Christmas raffle raised more than £17,000, and the Big Give Christmas Challenge hit a record £45,816 for medical research.



## Raffle winner

Elizabeth, aged 71, won first prize in the Retina UK Christmas Raffle in December.

She said: "I was thrilled to hear that I had won £500 in the Christmas raffle. It was a wonderful surprise especially in these uncertain times. I have known and followed Retina UK from the beginning, after being diagnosed with retinitis pigmentosa at the age of 28. It is truly heart-warming the amount of research and progress that is being made. I may not be in-line for renewal of my sight but the work being done will help thousands in the future."

Send us your snaps to [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk) – we'd love to see them!



*Let your glasses speak to you*



Envision glasses are AI for your eye. They use the power of speech to make everyday life more accessible for any visual impairment.



The thing about the glasses is it gives you the extra confidence to do those extra tasks that you would not do by yourself usually. It really brightens my capability as a blind man living independently. This is a game changer. Now if I can only get these glasses to clean my apartment."

Scott Haartmann  
Massachusetts, United States



**Camera** - An 8-MP camera with a wide field-of-view that captures every detail.

**Wifi and Bluetooth** - Keeps you connected at all times.

**Battery** - 5-6 hours with regular usage. USB-C supported fast charging.

**Audio** - Directional Mono Speaker, USB audio and Bluetooth audio.

**Robust and Light** - Water and Dust resistant. Weighs less than 50 grams.

Envision Glasses brings Envision's award winning software to smartglasses, enabling an unprecedented experience of hands-free and unobtrusive experience of accessing the visual world.

With features ranging from real-time text recognition to video calling, Envision Glasses opens the door for the future of wearable assistive technology.

From  
**£2,695.00**  
Ex VAT

## Features

- **Scan Text** - Turn any text into speech with Scan Text. Be it handwritten notes, books or your favourite recipes. In over 60 languages.
- **Video Call** - Call someone you trust to share your point of view, with Video Call.
- **Instant Text** - Read any short text that's in front of you with Instant Text.
- **Scene Description** - Get detailed scene descriptions anywhere. So you know what's around, every step of the way.
- **Face Recognition** - Find your colleagues or friends in an instant, with Face Recognition.
- **Other Features** - Includes object recognition, colour detection, batch scanning and the ability to export text

For more information or to arrange an online video demonstration, please email [info@sightandsound.co.uk](mailto:info@sightandsound.co.uk) or call **01604 798070** and choose **Option 1**



# Annual General Meeting notice

**Due to the COVID-19 pandemic our 2019 Annual General Meeting (AGM) was postponed with the agreement of the Charity Commission.**



The AGM will now be held on **Saturday 17 April at 2.45pm.**

Online, postal and telephone voting will be held in advance of the AGM, meaning all members who choose to do so can exercise their right to vote at a time, and in a format, that is accessible to them. **All members with voting rights will receive information on how to vote.**

We will present the results of the vote at our online interactive AGM meeting. All are welcome to attend the meeting where there will also be the opportunity to hear from our Chairman and Treasurer and to ask them, the Board and our Chief Executive questions. Register to attend the AGM at [www.RetinaUK.org.uk/annual-conference](http://www.RetinaUK.org.uk/annual-conference).

## Agenda

1. Welcome – Chairman Don Grocott
2. Apologies
3. Approval of the minutes of the previous AGM (result of online voting)
4. Presentation of the annual report and accounts for the year ended 31 December 2019 and 2020 overview – Treasurer Janet Crookes
5. Adoption of the Annual Report and Accounts for 2019 (result of online voting)
6. The appointment of the auditors (result of online voting)
7. Presentation of Retina UK activity in 2019 and 2020 overview – Chairman Don Grocott
8. The appointment of trustees (result of online voting)
9. Any other business

# Investing in the future

**Nurturing a new generation of scientists is a vital investment in the future of retinal disease research, so we are delighted to be funding, in collaboration with the Macular Society, a new PhD studentship at Oxford University, supervised by Professor Robert MacLaren.**



Student Elena Piotter began work on the project in October 2020 and will be investigating a potential Stargardt disease treatment, which could also be helpful for other inherited retinal conditions. Here, Elena tells us a little about her background, her aims for the project and hopes for the future.

"I completed my undergraduate studies at the University of California – Davis, where I started with a degree in International Relations but quickly realised I missed science so much that I added on another degree in Global Disease Biology. My biochemistry course and time spent working in a protein engineering lab really piqued my interest in laboratory work and understanding things on a molecular level; I loved learning how you could work with what nature had provided to try and solve problems.

"I decided to pursue a Master's degree in molecular biology at the University of Groningen in the Netherlands, which involved studying the biochemical "tools" that certain bacteria naturally

produce to enable them to interfere with genetic code via a molecular pathway known as CRISPR. (Bacteria use this as a defence against viral attacks.) As part of my studies, I came over to Professor MacLaren's lab to look at how this might be applied to gene therapy. This project was really exciting for me, as it exposed me to real-life outcomes and how they might help people.

"I initially knew very little about retinal conditions, sight loss or eyes in general – the most I had been exposed to was dissecting a cow eye in anatomy class! But within the first few weeks of the Master's project in Professor MacLaren's lab, I learned so much. I heard about the development of therapies that had progressed to clinical trials and about the diversity of people affected by inherited sight loss, which really added a new depth and purpose to the project. Professor MacLaren also let us watch some clinical trial surgeries at Oxford, which only added to that

sense of resolve and responsibility, and drove me to work harder. It also became clear to me that I wanted to continue the work with a PhD.

“My PhD project will investigate the use of CRISPR gene editing tools, similar to those I studied during my Master’s, to correct disease-causing faults in the genetic code. So far, gene therapy has allowed for the replacement of faulty DNA by using a harmless virus to carry healthy copies of the affected gene into retinal cells. However, a number of genes are too long to fit into these viruses, including the ABCA4 gene, which is associated with most cases of Stargardt disease.

“As an alternative to replacing the whole gene, I will see if we can use CRISPR technology to target the specific section of ABCA4 genetic code that is faulty and correct the error. Specifically, we want to try editing the genetic molecule known as RNA, which is a copy of the genetic instructions (DNA) that is carried to the cell’s protein-building machinery to produce protein. RNA makes a nice target for editing as, unlike DNA, it only exists temporarily, so our interventions would not introduce permanent change. This would potentially increase safety. RNA also offers more flexibility in terms of what can be targeted.

“There’s still a lot to learn, but exploring these new techniques allows us to

broaden the realm of what’s possible and enables more creativity in problem-solving. This approach to treatment also has potential for a number of inherited retinal conditions, not just Stargardt disease.

“I am really enjoying the whole PhD experience – lab meetings, discussions, and of course seeing results in the lab. It’s exhilarating when you’re checking to see if an experiment worked and an amazing feeling when it has been successful. On the other hand, it’s really frustrating when it doesn’t work and you have to repeat it. The other people in the lab are amazing though and overall it’s a fun and engaging process. I would like to say a huge thank you to the Retina UK supporters who have helped to fund this project – I am truly grateful to be able to work on it every day. Your donations are so generous and will allow us to undertake really important research.

“I really hope my work has an impact in some way for people living with Stargardt disease and other conditions; I hope it provides some optimism in the short term and contributes to a sight-restoring treatment in the long run. I would love to eventually meet some families affected by inherited sight loss – hopefully this will be possible after the pandemic has subsided. I’m also hoping to run for Retina UK in a fundraising event, so hopefully I might meet some of you then.”



# Help Retina UK from home

**Retina UK relies entirely on the generosity of you, our wonderful supporters, to fund our medical research and information and support services. We are so grateful to everyone who chooses to support our work, and we know you are brilliant at coming up with a whole host of imaginative ideas to raise vital funds and awareness for inherited sight loss.**

If you would like to support the charity during these challenging times but don't know how, we've put together this handy guide of easy, cost-effective stay-at-home ideas to get you started.

## **Raise money with your mail**

When you receive a letter in the post, save the stamp! There are lots of ways that stamps can raise funds – most are sold by weight but valuable or rare items will be sold to collectors separately. Carefully cut your stamps out of their envelopes, leaving 5-10mm around them. Once you've filled a jiffy bag or small box, (around 200g of stamps), send them to: **"Freepost RETINA UK"**.



## **Celebrate with Retina UK**

Make your birthday this year extra special and ask for donations to Retina UK in lieu of gifts or cards. With a Facebook Fundraiser or JustGiving page you can let your loved ones know that you're fundraising. Find out more:  
[www.RetinaUK.org.uk/birthday](http://www.RetinaUK.org.uk/birthday).



## **Remember Retina UK in your Will**

Including a gift to Retina UK in your Will may not cost you a penny today, and could be vital to help support our work in the future. Leaving just 1% of your estate to causes you care about (so your loved ones receive 99%) can make a huge difference. Find out more:  
[www.RetinaUK.org.uk/legacy](http://www.RetinaUK.org.uk/legacy).

# amazon smile

## **Shop with a smile**

Do you shop on Amazon? Using AmazonSmile raises money for Retina UK with every eligible purchase at no extra cost. If you're not already an AmazonSmile member, visit [www.smile.amazon.co.uk](http://www.smile.amazon.co.uk) to sign up. Each time you'd like to buy something from Amazon either visit this link to make your purchase or turn on AmazonSmile in the Amazon app settings.

# **ziffit.com**

## **Clear your clutter**

Virgin Money Giving & Ziffit have created a free online service to sell unwanted books, CDs, DVDs or games (non-computer), and donate the proceeds. Visit [www.ziffit.com/donate-my-stuff](http://www.ziffit.com/donate-my-stuff), scan your items and select to donate the value to Retina UK. If your items weigh 5kg or more Ziffit will collect them otherwise you can drop off your box at a local collection point when government restrictions permit. If you're already fundraising with Virgin Money Giving, you can link your Ziffit fundraising to your page – just get in touch with our team.

## **The power of your network**

Successful fundraising is often achieved by word-of-mouth, by speaking to friends, family and colleagues about the causes we care about and understanding if they can help. Do you or somebody you know work for a company that offers match funding? Perhaps you know someone who is part of a community group or is a Trustee of a Charitable Trust? If you are able to introduce anyone to our Fundraising Team, to chat about how they or their connections could help, we'd love to speak with them!



## **Take steps on your street**

Join our 10 for 10 Virtual Challenge and take on 10 miles in your neighbourhood. Set your route, walk or run and raise £10 for every mile! With help and guidance from a dedicated member of our team, join the challenge: [www.RetinaUK.org.uk/10for10](http://www.RetinaUK.org.uk/10for10).

## **Need help? Contact the team**

Email [fundraising@RetinaUK.org.uk](mailto:fundraising@RetinaUK.org.uk) or phone Simon on 07736 925174

# Chairman's update



***Look Forward* is a good positive name for a newsletter from a charity devoted to improving the future for people with inherited sight loss. It is also a rather valuable motto when so much in our lives is troubled. Perhaps now, more than at most times, we have much to *look forward to*. Spring and summer are not far away, inoculation and an easing of restrictions are on the horizon, as is some sort of normality.**

Here are a few more things that we in the Retina UK community can also look forward to: the first is the Annual Conference and AGM in April. Now, I know from experience that the announcement that the AGM is about to start is invariably followed by a surge of folk heading for their transport home, so I won't claim the AGM as a major attraction on 17 April. That aside, the conference itself has a stellar line up – see pages 8-9 – and, through the miracle of technology, we won't be leaving home to be there.

True, there is nothing like the buzz of linking up with old friends, meeting new folk, catching the gossip and chatting with the speakers and our splendid staff. But we must be cautious until we get the 'all clear' and so for this year, we meet virtually. I do hope you will be there especially as we will



be launching our new **Unlock Genetics website** on the day. Please sign up to attend – remember that you won't have to stand in line for a lunch box or queue for coffee! You will need to provide your own.

If you supported the Big Give and / or our Christmas Raffle, thank you. We really need – and enormously value – the continued support of our community. Please take every opportunity to help – there is still much to do. All the money raised from these appeals is devoted to our medical research.

Support is two-way. Our Helplines have been busier than ever during the pandemic. We have had twenty five percent more calls in 2020 and our volunteer helpline team report that these calls have been more for support than for the routine practical questions they usually get (see pages 6-7). A very big thank you for all those volunteers who 'man' the phone lines and emails, your work is very important and much appreciated. The helpline offers confidential support and gives the opportunity to discuss feelings or concerns with a trained volunteer who either lives with, or has a close family member with, inherited sight loss. So, if you or someone you know needs some help, call 0300 111 4000 or email [helpline@RetinaUK.org.uk](mailto:helpline@RetinaUK.org.uk).

Another thing to look forward to is

ending WFH (Working From Home). Our staff have adapted remarkably well to getting on with their jobs from their kitchen tables, bedrooms or garden sheds. Clearly, some jobs cannot be done virtually and so some staff have been furloughed. That's tough and so the Trustees are especially grateful for the gracious way those asked to furlough have got on with it.

We are also very grateful to Tina and all the office team for running their jobs via Zoom and yet continuing to deliver most of what Retina UK needs done.

Our Trustee meetings have been run on Zoom. They have been held more frequently as the charity has needed to respond to the swiftly changing circumstances during the pandemic. You may recall that in my last contribution to *Look Forward* I asked for anyone interested in joining the Trustee Board to contact the office. We have had a very encouraging response and we look forward to completing the recruitment process after the AGM.

Thank you for being part of the Retina UK community and for supporting us. Don't forget to ask if our Helpline team can help and do mark Saturday 17 April in your diary for the Annual Conference where the great programme will include the launch of our new Unlock Genetics website.

*Don Grocott*

# A sense of renewal and optimism

**Green shoots emerging from bare soil in the depths of winter are always a welcome sign that spring is coming. This year they'll be more welcome than ever, offering some tangible hope of lighter, brighter and better days to come.**

And this sense of renewal and optimism is just one of the positives that gardening can provide, which explains why so many people have found it a worthwhile and enriching activity throughout the coronavirus pandemic.

Gardening has proven benefits for our mental health. Growing plants to eat or admire is a meaningful activity that gives us something positive to look forward to. Nurturing plants through their growing stages offers us mental escape from daily worries, while providing a sense of purpose, satisfaction and ultimately achievement.

And these wellbeing benefits can apply whether you have a garden,

balcony or a windowsill. Just because you don't have a lot of space doesn't mean you can't get these mental health advantages from growing plants in pots and containers.

For people with sight loss, growing in containers can be more accessible as plants (and weeds) are easier to find and reach. Containers can be placed in sunshine or shade and are ideal for creating different soil conditions according to the needs of your plants. Pots can also be positioned at different heights to make the most of space and adjusted to your preferred working level.

Whether you fancy growing a few herbs on a windowsill or a vibrant display of flowering plants, vegetables, fruit, shrubs or trees, you can make it happen using containers. For those with gardens, researchers have found that people who spend time in them are significantly more likely to report general good health, higher psychological wellbeing and greater levels of physical activity than those who do not.

*"I have always been very hands-on, creative and have a knack for problem solving. Over the years of renovating our first house, I have never allowed my failing vision to hinder or stop me from carrying on with new DIY projects. I embrace modern technology by using talking tools like my talking tape measure and spirit level."*

*Retina UK Helpline volunteer Mark Baxter has completed a number of hard landscaping jobs in his garden.*

*By Mark Lang from Thrive*



Connecting with nature in a garden can alleviate mental fatigue, improve our ability to think, concentrate and make decisions. Importantly for the time we are living through, it can also help reduce stress, anxiety, depression and fatigue. Gardening has benefits for physical health too, as it's a form of exercise that can burn calories, help with weight management and strengthen major muscle groups. Common garden activities such as pruning, raking and sowing seeds can improve balance, co-ordination, dexterity and fine motor skills, while being in sunlight will reduce blood pressure and top up Vitamin D levels. Having a garden that engages the senses can have practical value as well as providing enjoyment.

Wind chimes can assist those with sight loss to find their way around a garden by providing a permanent audio marker, while at the same time being soothing. A water feature can do the same and provide a relaxing soundtrack. Yellow is a colour that is more readily visible to people with limited sight, so having bright flowers,

like calendula, on the edge of a path can assist navigation. Similarly, undertaking gardening jobs can be made easier if tools used for them have bright coloured handles that will be a contrast against the soil and foliage to help you find them.

The important thing to remember is that having sight loss need not be a barrier to enjoying gardening and all its physical and mental health benefits. Charity Thrive has worked with visually impaired gardeners for decades and has built up a wealth of knowledge and experience that can make gardening more accessible to people with disabilities and long-term health conditions.

From sowing seeds, pruning and watering to garden design and much more, Thrive's Carry on Gardening website has tips to help people with sight loss enjoy gardening. Find out more at [www.carryongardening.org.uk](http://www.carryongardening.org.uk) Thrive also offers publications and resources for gardeners with sight loss at [www.thrive.org.uk/shop/publications/sight-loss](http://www.thrive.org.uk/shop/publications/sight-loss).



# 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"/>
----------------------	----------------------	----------------------	----------------------	----------------------	----------------------	----------------------	----------------------	----------------------	----------------------

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: \_\_\_\_\_