

ISSUE 174 **SUMMER 2021** 

# LOOK FORWARD



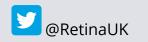
Inside this issue you'll find more details about our brand new website, Unlock Genetics (pages 6-7). We've also got a bumper research update which contains information about all of the latest research into inherited sight loss conditions (pages 16-18).

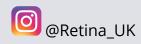
Summer is an ideal time to get more active and our friends at British Blind Sport have some excellent ideas which are suitable for all fitness levels (pages 22-23).

We also have the first in a regular series of 'Tech talk' articles from Jonathan Abro (pages 20-21). If there is anything you'd particularly like us to cover, please email the Look Forward editor, jane.russell@RetinaUK.org.uk.

/RetinaUKcharity







## Welcome to summer

As I write this I wonder if it will ever stop raining and we'll see the sun again. The forecast tells us the weather will get better soon so I hope that by the time you read this edition of Look Forward we'll be spending more time outside.

Our Annual Conference (pages 4-5) and Professionals' Conference (page 9) in April were a great success. Thank you to

everyone who attended and of course to our fantastic speakers. We're already starting to plan for 2022.

Those of you who attended the Conference will have heard that our wonderful Chair, Don Grocott, has now retired from the Board of Trustees. I will really miss Don with his vast knowledge of the optical sector and wish him



all the very best for his retirement. I am already working closely with his successor Martin Kirkup, whose son is living with Stargardt disease. You'll hear more from Martin on pages 14-15.

Our Information and Support events for the remainder of the year can be found on page 8. We very much hope that these will be in person rather than remote.

Finally thank you to everyone who has supported this year's Spring Appeal. There is still time to donate if you would like to help fund pioneering research (page 19).

Analladhen

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 · 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.

## Run with Retina UK



Whether you're a first time runner, seasoned pro or can raise a smile and cheer on our team we'd love to hear from you. Join Team Retina UK as we take steps to help support people affected by inherited sight loss to lead better lives today, and accelerate the search for treatments for the future.

#### **Virgin Money London Marathon**

#### **3 October 2021**

Reach for your trainers and run the 2021 London Marathon. Soak up the incredible atmosphere on a route that includes the Cutty Sark, Tower Bridge, Big Ben and Buckingham Palace! The deadline for applications for a charity place is 9 July 2021, so register today: www.RetinaUK.org.uk/londonmarathon.

#### Volunteer with us

Do you have a passion for photography? We hope to capture photos of our runners in action. Not only will these be treasured mementoes for our runners but they'll also help us to advertise our running events in future, helping us to do more of what we do best. If you're a dab hand with your DSLR and local to London, please get in touch.

If you're happy to spend a few hours outside and want to be part of the electric atmosphere cheering on our runners at our London Marathon cheer-point we'd love to hear from you. You don't need to have any previous

experience, just come with a smile and be ready to clap, cheer and celebrate. Call Simon on 07736 925174 or email simon.taylor@RetinaUK.org.uk.

#### **Royal Parks Half Marathon**

#### 10 October 2021

This stunning race takes in some of the capital's world-famous landmarks on closed roads, and four of London's eight Royal Parks – Hyde Park, The Green Park, St James's Park and Kensington Gardens. With sustainability at the heart of this race, you'll find FSC certified wooden medals, race shirts made from recycled bottles and bamboo, and biodegradable water capsules amongst other innovative ideas! Find out more:

www.RetinaUK.org.uk/royal-parks.

### Run in your region

As well as many of the well known races we also have places available in hundreds of local runs. From family fun runs and obstacle courses to half and full marathons, wherever you live, you can run as part of Team Retina UK! www.RetinaUK.org.uk/run-local.

# Retina UK Annual Conferen

Thank you to our speakers, sponsors and attendees for a really successful 2021 Annual Conference on Saturday 17 April.

Our 2020 Conference was sadly cancelled due to the restrictions around the COVID-19 pandemic and we took a decision early in 2021 that this year our conference would be held online. We missed getting together with you all and chatting over a coffee but on a positive note, it meant more of you were able to join us, including many for the first time. More than 400 delegates registered for the event and 98% said they would either attend, or recommend future Retina UK events.

The focus for this year was genetics, an area where research is currently very active.

**Professor Alison Hardcastle** kicked off the day with a potted history of genetic research in inherited sight

"I've been a member since 1979 and I have never been to a conference because of the distance and not having anyone to accompany me that might be interested enough to attend the conference. But this time I was able to attend online and I really enjoyed it and thought the presentations were outstanding."

loss and how genetic variations can disrupt that genetic code. She shared her enthusiasm and excitement of working in research at a time when technological advances allow us to carry out work that we could never have dreamt possible. Genetic therapies, such as 'readthrough' therapies (which remove the stop mutations in genes) have the potential to target other conditions and crossover and collaborative work is seeing real progress.

"All the guest speakers were very interesting and all had promising and optimistic research, it makes you feel like there is light at the end of that very dark tunnel after all and it makes all the fundraising and campaigning even more worthwhile. Fantastic all round."

Georgina Hall introduced our delegates to her work as a Consultant Genetic Counsellor. She provides information about genetic conditions and offers support to her patients to help them understand their condition, their inheritance pattern and what genetic testing involves. Individually genetic conditions might be quite rare but if you pull all rare disease together, it is calculated that around one in 17 people have a rare disease.

One of the highlights for the Retina UK team was the launch of our new

# ce 2021

Thank you to our 2021 Conference sponsors, Biogen, Janssen, Novartis, Okuvision and ProQR. Your support is much appreciated.







Unlock Genetics resource at the Conference. You can read more about that on page 6.

Samantha De Silva gave a fascinating update about the latest research into inherited retinal dystrophies. There is a huge amount of work going on in this area from gene therapy, gene editing, optogenetics, oral medications and neuro protection strategies.

Conference recordings in both audio and video formats are available on our website: www.RetinaUK.org. uk/recordings. If you would like to receive the audio recordings on CD or memory stick please phone 01280 821334 or email info@RetinaUK.org.uk.

There was a great deal of interest from our delegates in representing the inherited sight loss community through activities like focus groups, surveys and research projects via the Retina UK Panel. You can find out more about the Panel and register to take part by visiting: www.RetinaUK.org.uk/more-info.

At the close of the day we had the sad task of saying goodbye to our Chair of Trustees, Don Grocott. More about Don and our new Chair, Martin on page 15.

We are provisionally planning to hold our 2022 Annual Conference on Saturday 9 July in Birmingham. More information will be shared as soon as it is available.

# New genetics website helps to

High quality information on genetic testing and counselling for families affected by inherited sight loss is now available in one place thanks to the launch of an innovative new website, Unlock Genetics (www. RetinaUK.org.uk/genetics).

The site aims to increase the level of awareness of genetic testing and genetic counselling amongst people living with inherited sight loss conditions, empowering them to make fully informed decisions about their lives, healthcare and family planning. It provides clear, trustworthy and balanced information and has been developed with significant input from experts in the field and also those who live with inherited sight loss.

Of the 1,000 people who responded to the Retina UK Sight Loss Survey in 2019, 43% said they were 'not aware' of genetic testing or that they were 'aware of it but it is not available to me'. The charity estimates 85% of its community do not currently have a genetic diagnosis.

Tina Houlihan, Chief Executive of Retina UK said the site aimed to address the issue of a lack of awareness and enable people to make informed choices. She said: "Far too many of our community are still unaware that genetic testing and



counselling is available to them through the NHS – our new Unlock Genetics website aims to change this.

"Being diagnosed with an inherited retinal condition often means there is a great deal of uncertainty ahead but, with access to the right information, there are some areas that people can make informed decisions about and have some control over. This includes genetic testing and counselling, which can lead to a more accurate diagnosis, a better understanding of inheritance patterns (and the chances of future generations being affected), and even offer the potential to take part in research trials and access treatments in the future."

Novartis Pharmaceuticals UK, who funded a grant for this project, believe

# unlock choices

Unlock Genetics will act as a 'valuable resource'.

"The patient burden is high for those born with inherited retinal dystrophies (IRD) and the debilitating nature of these conditions can place a life-long physical, emotional and financial burden on patients and their families," said Chinmay Bhatt, Managing Director UK, Ireland & Nordics for Novartis Pharmaceuticals.

"Learning more about the type of IRD via genetic testing can equip patients and their families to better understand their condition and guide disease management together with their clinician. Retina UK's Unlock Genetics website offers much needed information around the potential benefits of seeking a genetic diagnosis, and we believe it will act as a valuable resource for the community."

The benefits for those living with an inherited sight loss condition having a genetic diagnosis and accessing genetic counselling can include:

- Feeling better informed about their condition and the reason why they and their family have been affected.
- Being given a more precise diagnosis and a possible indication of how their sight loss might progress.
- Confirmation of inheritance pattern, providing a clear understanding of risks to children and grandchildren

- and opening up choices around family planning.
- Potentially becoming eligible to participate in the increasing number of clinical trials and being able to access treatments when they become available.

"The launch of this website is a significant step forward in contributing to unlocking exciting opportunities available from the rapidly developing understanding of genetics, leading to further clinical research trials and possible treatments for more retinal dystrophy sufferers. I hope the website will help to raise awareness of the importance of genetics and explain what genetic counselling and testing are and how to get these services through the NHS."

Martin, who lives with inherited sight loss and volunteers on the charity's email helpline. He was on the community review panel.

Inside this edition of Look Forward you will find a postcard sized flyer promoting Unlock Genetics. More copies are available on request, along with a poster, ideal for use in healthcare settings. An audio transcript of the website is available in CD or memory stick format and we can also provide printed copies on request. Please email info@RetinaUK.org.uk or call 01280 821334.

## Connect with us and each other

#### **Dates for your diary**

Following on from the success of our Annual Conference we are delighted to advise that we are planning to deliver Information and Support events in the second half of this year. The dates and locations are as follows:

- Retina UK Information Day, London Saturday 25 September
- Retina UK Information Day, Cardiff Wednesday 13 October

More information will be available soon at www.RetinaUK.org.uk/info-events.

#### Helpline upgrade: one year on

It is now a little over 12 months since we upgraded our helpline and introduced the new local rate number. Calls to the helpline have increased by more than 25%.

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

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

We have also introduced a feedback survey at the end of the call. Of those

who completed the survey, 100% have said that they would use the Retina UK helpline again or recommend it to others who may benefit.

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

### **Supporting each other**

Our local peer support groups are currently being held online. You can find details about the next scheduled meetings on our website: www.RetinaUK.org.uk/groups.

"It was brilliant, all of us no doubt would say that and even after we can get back to holding our usual meetings I can see these Zoom meetings continuing. We are spread out in Scotland and many of us can't make an actual meeting so this is a fantastic alternative, well done."

Jim McLean

## Professionals' Conference moves online

Almost 200 members of the professional community working with people living with inherited sight loss conditions joined us for our first online Professionals' Conference in April.

Delegates were from a range of professions including Eye Clinic Liaison Officers, Rehabilitation specialists, Teachers, Ophthalmic Nurses, Third Sector Professionals and Genetic Councillors.



They heard from Dr Panagiotis Sergouniotis, NIHR Academic Clinical Lecturer in Ophthalmology at the University of Manchester. He

explained the reduction in the cost of DNA testing has transformed the way we do genetic testing, the way that we diagnose people with inherited disorders, and how we manage them.

Clinical Psychologist Dr Ian McCubbin



encouraged the professional community to start a conversation with their clients about mental health. He urged them to notice remarks which

could indicate that they might be struggling around their emotional wellbeing. It could be something related to sleep, appetite, relationships with other people and withdrawing socially.

The Retina UK team introduced delegates to the new Retina UK Unlock Genetics website and encouraged them to share the resource with their clients. More about Unlock Genetics on page 6.





Professor James
Bainbridge was joined
by Jake Ternent, one
of the first people to
receive the Luxturna
treatment for
mutations in the gene
RPE65, to discuss the
journey to a treatment.
Something which Jake
described as having
changed
his life.

"Fantastic conference, not only the slick professional manner of the online conference but the content from your speakers was informative, moving, educational and incredibly useful."

Conference Delegate

The recordings (audio and video) are available on the Retina UK website: www.RetinaUK.org.uk/recordings.
We are provisionally planning to hold the next Professionals' Conference on Friday 8 July 2022, please save the date.

# The difference we











Miles completed by Virtual Challenge fundraisers



Fundraising amounts raised:

£35,500 BBG Appeal £45,962 the Big Give £17,169 Raffle

Thanks to all those who generously supported our work in 2020. Together we are able to make a real difference to the lives of thousands of people with inherited sight loss conditions.

# made in 2020









We are in touch with



People affected by inherited sight loss



New people joined our charity



Helpline calls and emails responded to



People attended our local group meetings



Podcast plays



Online support group members



43,230 🖒 1,021

Copies of Look Forward shared

**New Followers on Social Media** 







Kiz and Andrew completed the Big Step Challenge – walking 25,000 steps between them each day for 25 days. Together they raised a fantastic £440!



Gwyneth and Samantha took on the Captain Tom 100 with their baking challenge. They baked 256 cupcakes and raised an incredible £342!

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



Shannon and Patrick trekked the 154km West Highland Way! This photo was taken at the end of the trail in Fort William after completing the route and raising an amazing £3,195!



Sarah walked for 22 and a half hours completing the 100km London to Brighton Ultra Challenge and raised over £2,300! Thank you Sarah!



## A lasting legacy

Thank you to Helen Marie Thompson from Kent for recently updating her Will to include a gift for Retina UK. Here, she explains why:

"My brother and two nephews all have the inherited eye condition retinitis pigmentosa (x-linked RP2). My brother has sadly lost all his vision and is now registered blind; my two nephews are 27 and 20 years old and they are both gradually losing their vision. They will eventually lose all of their vision and this breaks my heart.

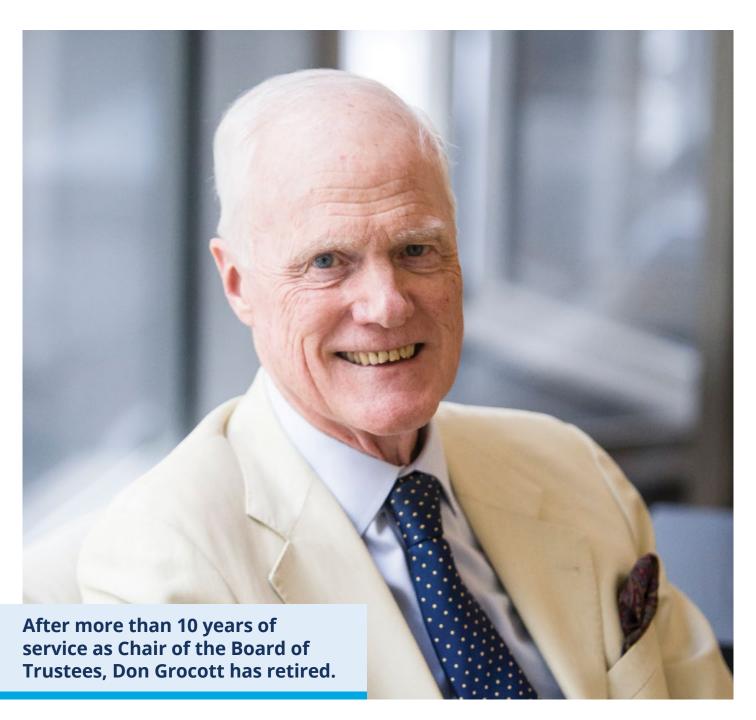
"RP has a devastating lifelong impact on those with the condition, their families and friends. Due to the amazing work undertaken by Retina UK in providing support for people with eye conditions and vital work into research, many people with RP can live independently and make positive contributions."

"If leaving a gift donation in my Will to Retina UK helps just one person to have the precious gift of sight then my contribution will be worth every single penny."

If you would like to find out more about leaving a lasting legacy, please visit: www.RetinaUK.org.uk/legacy, or contact Alice on alice.capper@RetinaUK.org.uk or 07841 481423.

Send us your snaps to fundraising@RetinaUK.org.uk - we'd love to see them!

# A fond farewell and a warm



Don was appointed to the Board in early 2009 and as Chairman in June 2011. Don has seen the charity evolve to better meet the needs of our community over the years. He saw the transition of the charity from the British Retinitis Pigmentosa Society (BRPS) to RP Fighting Blindness in 2014 and from

RP Fighting Blindness to Retina UK in 2018. His calm and measured support has been particularly valuable over the last year, not just to our Chief Executive, Tina Houlihan, but to the whole team.

Don, who retired at our Annual Conference in April, said "I have enjoyed

# welcome

my role with Retina UK and know how much that has been enhanced by our wonderful supporters.

"I won't lose touch - Retina UK will continue to be very important to me and so I will follow its progress with very real interest.

"Very many thanks to you all."

Don is succeeded by Dr Martin Kirkup who joined the charity earlier this year as a Trustee. He took over as Chair in April.

Martin said: "I am honoured to have the opportunity to take on the role of Chair of the Board of Trustees. Having a son with Stargardt disease has made me acutely aware of the critical need to drive forward the search for cures for inherited sight loss and the equally important need to support all those affected by sight loss in their everyday lives.

"I want to join my colleagues in thanking Don for his many years of service to Retina UK. He has accomplished much and built a well-deserved, deep-felt respect from all those that have had the pleasure of working with him. We wish him well in his retirement.

"He will be a tough act to follow, but I am taking it on full of enthusiasm and motivation. I am excited about the future for Retina UK, it has a strong



team leading it, an amazing group of volunteers and members and a highly supportive Board of Trustees. I want to bring the insights I have built over a long career driving growth and leading marketing in the corporate world to the service of Retina UK to assist its future development.

"The manner in which Retina UK has weathered the challenges of COVID-19 is admirable and consequently we are emerging in a strong position to make even greater progress going forwards. The future is exciting!"

# Research brings hope for the



So said an attendee of Retina UK's recent Annual Conference, where we heard from Professor Alison Hardcastle and Dr Samantha de Silva about the progress being made by researchers, from gene discoveries to treatment development. Here's a roundup of just some of the exciting work going on in labs and clinics around the world.

**Cracking the code** 

For around one third of people with an inherited retinal condition, NHS genetic testing does not clearly identify the genetic fault underlying their sight loss. This is because their condition is caused by a change to the genetic code that scientists have not yet been able to recognise or clearly understand as a cause of retinal damage. For these

individuals and their families, finding these hidden mutations could mean a better understanding of their sight loss, access to choices, and ultimately, the development of treatments.

Professor Hardcastle and her colleagues in the UK Inherited Retinal Dystrophy Consortium (UKIRDC), which is funded by Retina UK, have been using cutting edge technology to read through the entire genetic code of hundreds of people with inherited sight loss and pick out newly identified changes that could be causing problems. The consortium has brought together scientists with complementary fields of expertise from leading UK centres.

# future

Professor Hardcastle explained: "This has enabled us to create an efficient infrastructure where we can share the clinical information and the genetic data and all our combined knowledge and expertise so we can have really informed discussions and try and interpret what's going on in the genomes (full genetic codes). This has been very successful; we've discovered many new genes and different variants that we weren't expecting."

Professor Hardcastle also explained how she is using stem cell technology to create living models of the retina in the lab, enabling her team to better understand the damage caused by a particular genetic fault and investigate ways to fix the problem.

She went on to say: "We can now edit genes, so when we've got the stem cells we can actually edit the DNA and make mutants (to replicate disease) or actually try and cure the mistake by correcting it. This is proving to be an incredible tool; the limit here is just your imagination in terms of what we can do."

#### **Towards treatments**

Meanwhile, Dr de Silva provided a whistle-stop tour of the various treatment approaches being explored. "It's really a testament to the huge amount of work that's going on in this area that I've got quite a lot to talk about" she told us.

**Gene replacement therapy:** This generally involves using a harmless virus to carry healthy copies of the affected gene into retinal cells. One such therapy, Luxturna, is already available on the NHS to treat sight loss caused by faults in the RPE65 gene; others are progressing steadily through clinical trials, including those for X-linked RP (RPGR gene), choroideremia and achromatopsia. These therapies target specific genes, so a genetic test result would be essential to determine eligibility, and can only work in surviving photoreceptors, so relatively early in the progression of a condition.

Antisense oligonucleotides / RNA therapy: This approach could be used to treat conditions inherited via an autosomal dominant pattern, or those caused by faults in very large genes, where gene replacement therapy can be challenging. It involves creating special molecular "patches" to cover up a faulty section of genetic code, enabling the retinal cell to read around the fault and produce a protein that still works to some degree. This is another highly specific approach requiring a genetic test result and a reasonable proportion of surviving retinal cells. It's undergoing clinical trials for Usher syndrome (USH2A gene), LCA type10 (CEP290 gene) and autosomal dominant RP (RHO gene).

continued on next page

## Research brings hope for the future

Gene editing: This uses a biological tool called CRISPR to snip out and correct specific spelling mistakes in the genetic code. Like RNA therapy, it could potentially be useful for addressing faults in very large genes like USH2A and ABCA4, which are associated with many cases of Usher syndrome and Stargardt disease respectively. It has reached early stage clinical testing for LCA type10.

Oral medications: All of the approaches mentioned so far are administered via injection into the eye. However, it may be possible to treat some conditions with medicines that reduce the build up of toxic substances that can occur in retinal cells when certain genes and proteins malfunction. This approach is undergoing clinical testing in Stargardt disease.

Stem cells: Retinal progenitor cells are "baby" retinal cells that have yet to fully mature into specialist photoreceptors. Researchers are carrying out clinical trials to see whether injecting them into the eye can provide the existing cells with nourishment and support, or even if they can take over some of the work. This treatment doesn't require a specific genetic diagnosis, but the results of the clinical trials will help determine whether stem cell therapy is most helpful at any particular stage of sight loss.

**Optogenetics:** A number of research groups and biotechnology companies are investigating this exciting approach for treating the later stages of sight loss, when vision is minimal. It involves providing cells in the retina that don't normally sense light but are unaffected by the disease process, with genetic instructions for building light sensitive proteins. These cells can then respond to light and send simple images to the brain. This could provide limited perception of objects, perhaps restoring some independent mobility to a person with severe sight loss, but would not enable reading, TV viewing etc. Many optogenetics systems would require the use of special glasses / goggles. You can read more about the most recent developments in optogenetics on our website: www.RetinaUK.org.uk/research-news.

The clinical trials process is long, and it could be a few more years before we see more treatments become available in the NHS, but with so many avenues being explored, there is a huge amount of hope for the future.

Please consider making a donation to Retina UK today, to fund pioneering research that will lead to the treatments of tomorrow. Every contribution will make a difference. Visit www.RetinaUK.org.uk/SpringAppeal2021.

**Spring Appeal** 

There's still time to donate

In May, many of you will have received a letter from Jake Ternent, the first person in the UK to receive a licensed treatment for his inherited retinal condition.

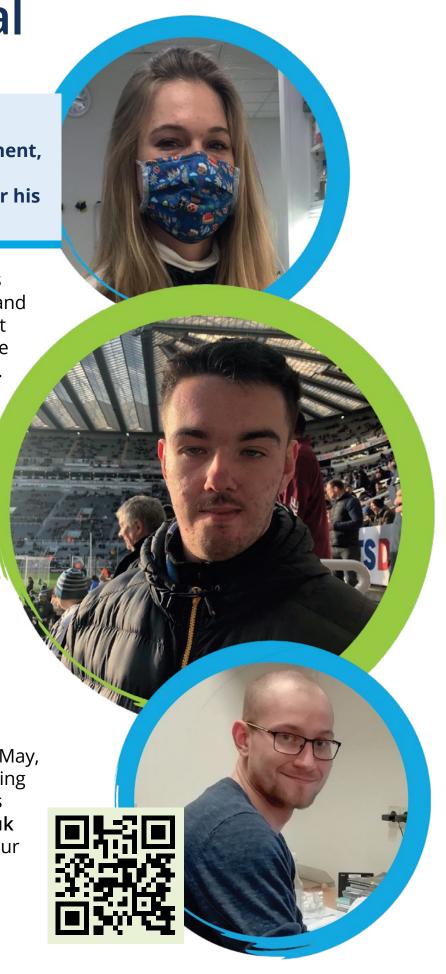
He talked about the impact of this historic breakthrough on his life, and encouraged everyone to give what they can so that treatments can be developed for many more people.

So far, an amazing £10,120 has been raised to fund the pioneering research needed to make this happen. We are so grateful to everyone who has chosen to contribute. We're a little over half way with just under £10,000 to go.

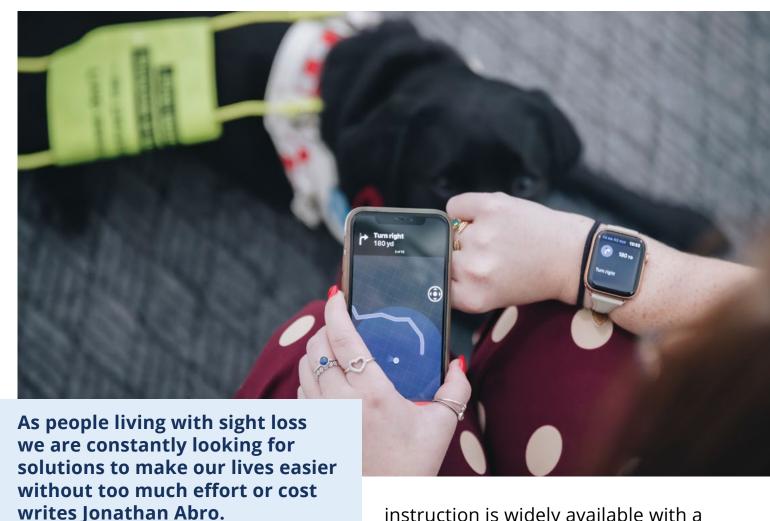
If you would like to donate, you can do so at www.RetinaUK. org.uk/SpringAppeal2021, or by using the form at the back of this newsletter.

If you didn't receive the appeal in May, and would like to receive fundraising information in future, just drop us an email on info@RetinaUK.org.uk or call 01280 821334 to amend your communication preferences.

Thank you



## Let's talk about tech



Over the last 20+ years of my sight loss I have been on this same journey. I am delighted at how much is available to us. Ten years ago I would not have believed such progress would have been made and that some sight loss solutions would become mainstream in the way they have.

Over the next few newsletters I'll share some of my favourite apps and solutions with you. I won't be providing user guides but rather sharing what I find useful. Detailed

instruction is widely available with a simple Internet search.

One of the best pieces of advice I have ever had from another VI person is: learn to touch-type now and learn to use assistive tech before you need it.

Being a few-fingered typist I took this advice seriously and tried various tutors. I found Azabat to be the one for me and within three weeks of tuition I was a touch-typist. It was definitely worth the effort as we use keyboards every day whether on smartphones, tablets or computers. Try these typing tutors to find the one that suits you:

- Azabat: www.azabat.co.uk/typing.html
- BBC kids: www.bbc.co.uk/teach/ skillswise/typing/zjqm92p
- Mavis Beacon: www.mavisbeaconfree.com

Smartphones are a good place to start and, although I use an iPhone, the accessibility features and equivalent apps are available on Android phones too which means that the choice has become much wider as to which smartphone to buy.

When it comes to apps, remember to always try free apps first. If you think the paid-for apps have better features for your needs, give the free trial a go first to 'try-before-you-buy'.

**Seeing AI**, a free Microsoft app, is one of my favourite apps and one I use

frequently. Using artificial intelligence, each channel has a different function allowing us to:

- Read the post as it arrives rather than waiting for help,
- Scan a document to read or save for later use,
- Recognise supermarket products by scanning barcodes,
- · Check on the colour of something,
- Sort out currency in your wallet before going out,
- Determine how light or dark the room you are in is, and,
- Still being developed, read handwriting, scenery description and identify or describe a person with some hilarious results so to be taken with a pinch of salt!



Jonathan Abro lives in central London and is a Freelance IT Professional specialising in IT Project Management of large-scale software development and IT Accessibility for all forms of disability. He is a Trustee of VocalEyes, the Charity providing Audio Description to The Arts, a member of the London Sight Loss Council, a Tech Support Volunteer with the RNIB and a member of Retina UK. Jonathan has RP and, since being diagnosed in 1996, has lost all but a bit of his peripheral vision. He is passionate

about travel with highlights including camping on the ice of Antarctica, standing on all seven continents and, to celebrate his 50th birthday (while raising research funds into RP and raising awareness of sight loss), he climbed Mount Kilimanjaro.

# Get active this summer

At British Blind Sport, we take pride in making a visible difference through sport because we know that taking the first step towards participating in recreational activities can help to change people's lives for the better. Research shows that regular exercise can relieve stress, improve sleep quality, boost the immune system and much more. As the warmer weather arrives and we gradually emerge from lockdown, now is an excellent time to try a new sport or activity.



There are numerous events throughout the year, many of which are free, that provide a supportive environment for blind and partially sighted people to try different sports. You can find inclusive activities in your area by using our Activity Finder. Simply choose an activity you are interested in, enter your postcode, and the Activity Finder will display a list of local providers. We hope you'll find this a useful resource, whether you are starting a new challenge, looking to improve your fitness, or just wanting to meet new people. Try it for yourself by visiting: https://britishblindsport.org.uk/ activity-finder.

Do you want to start running or are you an experienced runner looking for support? We've partnered with England Athletics to provide a quick and easy way to 'Find A Guide' to help blind and partially sighted runners lace up and get moving. Use our Find a Guide database to search for guide runners near you. https://runtogether.co.uk/get-involved/find-a-guide.

Over the past year, BBS has collaborated with inclusive trainers to develop a programme to keep our members and service users #ActiveAtHome. Our programme includes high-intensity strength training,

## Spotlight on British Blind Sport

high intensity interval training (HIIT) and boxercise as well as low-impact yoga and Pilates classes. Following our week of live workouts at the beginning of every month, our instructors upload a follow-on exercise session to our YouTube channel. The idea is that you repeat the same session on the same day each week to build a weekly routine and see improvement. For more information on the programme, visit: https://britishblindsport.org.uk/active-at-home.

You can sign up to receive our weekly Active At Home mailshot by visiting: https://bit.ly/BBSMailingList.

Summer months provide the best conditions for getting outside, getting



some fresh air and focusing on your wellbeing. Trying out a different activity can spark a new passion or interest, opening up a world of possibilities. Sport can provide you with an outlet, connect you to a network of support and allow you to meet other people in your community who share the same interests. So, what are you waiting for? Get stuck in, try some new things and see how you get on!



### We are so grateful for all donations to our work **RETIN** 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. Thank you. I enclose my cheque for £\_\_\_\_\_ payable to Retina UK. I would like to make my donation of £ by debit/credit card. My donation is for the Spring Appeal. Card Holder Name: Maestro Card Type: Mastercard Delta Expiry Issue Number Start Date: Date: (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/regular-giving 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) If you gift aid your donation, the charity will receive an extra 25p for every £1 that you give! I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on my donations it is my responsibility to pay any difference. I understand the charity will reclaim 25p of tax on every £1 that I have given. Please see HMRC for more information.' Signature: Start date:

