

# JULY 2024 NEWSLETTER

Dear friends and supporters

We've had a really active period of fundraising as many more people become aware of the value of vision research. This is an incredibly exciting time for all of us who are working to improve visual outcomes for patients who have been diagnosed with blinding eye diseases. Thank you to those of you who supported my Cambridge Half Marathon and, of course, for all your donations and regular gifts. Between us we have raised over £5m for vision research through Gift of Sight over the last twenty years.



A large proportion of this can be attributed to generous legacy gifts but the rest has been raised through sheer hard work and amazing fundraising events set up by patients and their families. Recent examples include an 80 year old supporter who climbed Scafell Pike in Cumbria to celebrate his birthday, a visually impaired patient walking the full length of Croatian Long Distance Trail and the father of a child with albinism, who is preparing to run 7 marathons in 7 days in September. I'm delighted to hear that some of our research team, together with our Gift of Sight assistant Jennie, are planning to undertake the Three Peaks Challenge, also in September. It looks like a busy month!

I have written an article overleaf to show how much our research is helping move towards treatments for both wet and dry forms of age-related macular degeneration (AMD). Gift of Sight has been instrumental in supporting salaries to push our research forward, as well as purchasing consumables, imaging equipment and kit for the laboratories. I was also involved in a study relating to home testing for wet AMD. This showed that none of the home-monitoring vision tests evaluated were helpful in detecting relapse or new signs of wet AMD. The details are shown here.

In other work, we are currently participating in clinical trials of new gene therapy treatments for both the dry and wet forms of AMD. If these trials are successful we might only have to treat a patient once, as opposed to the sometimes hundreds of injections patients might otherwise need! We are very grateful to all the patients who help us with this work, many of whom also support the Gift of Sight Appeal.

My team and I really do value your enormous support and look forward to catching up with many of you at our events. Thank you again for your tremendous interest and generosity.

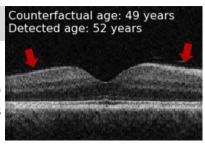
With best wishes,

Andrew Lotery MD, FRCOphth Professor of Ophthalmology University of Southampton

Andrew Lotery

### **Professor Andrew Lotery: Age related Macular Degeneration (AMD)**

In 2018 I led a collaboration of researchers who were awarded a £4 million grant from the Wellcome Trust entitled "Deciphering AMD by deep phenotyping and machine learning: the PINNACLE study". This study was developed with the aims of better understanding the processes behind the progression of Age-related macular degeneration (AMD) and



identifying the individual risk factors that contribute to this. AMD is a very common cause of blindness but, unfortunately, we don't know who will progress to the sight threatening stage of the disease. Some patients progress slowly or not at all and others quickly.

I am leading this study, working with colleagues in the UK, Europe and the USA. By teaching computers to analyse over 500,000 high resolution images of the inside of the eye, we can identify any changes that appear in the eyes of patients with AMD. We have proved that computers can reliably predict how an eye changes in structure as it ages and we can now see which layers of the retina (the tissue that senses light in the back of the eye) thin first. This should help us develop new types of early treatments and enter the most appropriate patients into clinical trials.

As part of this study we are currently training computers to give an accurate verbal description of what a retinal image shows and hope this might ultimately help high street opticians identify which patients need urgent referral to hospital for their AMD. This will ensure that patients are directed to the right hospital clinic, which currently does not happen in around four out of five cases!

We are also investigating how AMD progresses by carefully following up 400 patients with early AMD and checking how each layer of the eye changes over time. This should help us identify which patients are at high risk of needing treatment. I am really grateful to them for helping us with this work.

This is the largest grant that has been awarded to the Vision Group in Southampton to date and the application was built on our many years of research into AMD. One of the conditions of the grant was that we made a financial contribution to the research. Gift of Sight made this possible by contributing over £100,000 towards a retinal camera that we needed for this project. I think this really highlights the benefit of the Gift of Sight appeal. Thanks to this funding we were able to access £4 million of funds for research, which is a 40-fold return on the investment!

# **Natalie Clarke: PINNACLE Trial Manager**

I joined the PINNACLE team in October 2022, following eight years working on oncology clinical trials for the University of Southampton.

It is my responsibility, as Trial Manager, to oversee and coordinate all study activity, whilst also making sure everything runs smoothly and within the project timelines. A large part of my role involves liaising with our 12 study sites and 6 collaborating institutions across the UK and Europe, in order to check progress and resolve any queries. I also maintain the central visit records of our 429 intermediate AMD patients, who attend their local study site every four months to undergo specialised testing and imaging of their eyes. The purpose of these visits is to identify and monitor any early structural changes,



which we hope will give us more information about how and why AMD develops over time.

My other responsibilities can include anything from managing study finances, creating internal study newsletters, to updating study documents and writing protocols for ethics board review.

Most recently I have also been responsible for setting up our 'SUMMIT' extension project; an additional 2-year follow-up period which will provide further valuable insights into the mechanisms of AMD progression. My favourite part of the role is being able to work closely with our study site teams and ensure we are conducting our research to the highest possible standard. It's also very rewarding to hear that our participants really appreciate being part of the trial, and even enjoy attending their study visits!

This is all only possible with the hard work of our study teams, the dedication of our participants, and the support we receive from our funders, including the Gift of Sight Appeal. I look forward to seeing how the results of both PINNACLE and SUMMIT will help to shape the way AMD is diagnosed, monitored, and treated in the future.

# **THANK YOU to all our generous fundraisers**

#### Bach's St. John Passion, 29th March at Winchester College Chapel

Over 200 guests joined us for this amazing 300th anniversary performance, generously organised for us by Jon Newman and conductor Andrew Hayman. This was a truly moving event and we are hugely grateful to Boots Opticians, Eastleigh and Mrs Sarah Saunders-Davies for their generous sponsorship and to Butterflies Healthcare for covering the cost of our programmes. This amazing support, together with generous donations on the night, helped us raise £4,500 for Gift of Sight.



#### Professor Andrew Lotery's Cambridge Half Marathon with daughter Lizzie

Well done Prof and Lizzie! Our thanks for raising £670 to help the research team - and for completing the run in under two hours!

#### Second Wind Clarinet & Saxophone Quartet, Portswood Residents Pavilion

Our grateful thanks to Hugh Hadfield and his fellow performers for taking us on a musical journey from Classical to Swing with Ragtime along the way. The Pavilion was full to capacity, we enjoyed afternoon tea and listened to a talk by Professor Andrew Lotery. A great team effort by all involved and a bucket collection at the end of the afternoon raised an amazing £1500.



## **Portswood Knitwits Charity Fundraising, Portswood Library**

Ailsa spent a lovely morning with the ladies of Portswood Knitwits when they held a sale of their work. People who came to use the library bought many of the beautifully made garments and toys. This was an amazing community event to join in with and thank you for the £325 raised for Gift of Sight.

#### Josephine Bates, Great West Run

Jo is a final year medical student working in Exeter who has previously run for Gift of Sight. She was very happy to have raised £386 "with everyone's help" and also achieve a new personal best time for the half marathon of 2:06:29. Win-win! Thank you for helping us again Jo.

#### Rodney Mansbridge, Scafell Pike

Rodney, who has fundraised for us before, decided to celebrate his 80th birthday on the 6th June by climbing Scafell Pike to raise funds for Gift of Sight and Help for Heroes. Supported by family members, Rodney found the climb very challenging and he wasn't rewarded by any views of the surrounding countryside, as he arrived at the summit in thick cloud and freezing hailstones! Huge congratulations from us all Rodney and thank you for raising more than £3000 in total.



#### **820 Spirits Gin Tasting Event**

We enjoyed an event at 820 Spirits, hosted by Tom Simpson, who explained the art of creating 'perfectly balanced botanicals in spirits'. Talking guests through four different types of gin we enjoyed a sociable evening with canapes and a talk from Professor Andrew Lotery. It was lovely to return to Lymington and we hope to hold more events in the area in the future.



#### Walk for Wiggly Eyes 4

Our grateful thanks and HUGE congratulations to Mike Larcombe, who has nystagmus, on undertaking the massive 1400 mile hike along Croatia's scenic Long Distance Trail. Completing in an impressive 54 days, Mike has been posting amazing updates, many reflecting upon the kindness of strangers he's met along his way. Mike has raised £1597 for Gift of Sight so far and if you have a few pounds to spare we know he'd love some help increasing this sum on his <u>JustGiving page</u>.

# And coming up..! Full details on www.giftofsight.org.uk/events

# Southampton Archery Club Charity Day, Saturday 20th July 2024, 10am-4pm, Hardmoor Sports Ground, Eastleigh, SO50 9HT

We would love you to join us at the Club's main charity fundraising day, which promises to be lots of fun for all the family. Club members will be undertaking a 24-hour 'shoot' and will be encouraging everyone to test their skills with a bow and arrow. Enjoy 'have a go archery', 'archery tag', BBQ, refreshments and a raffle. All ages and abilities welcome! Entry is free, there's no need to book in advance but please do come and chat with us! For more details and to help by donating, please visit their <u>fundraising page</u>.



#### Joe Marsden's 7 Marathons in 7 Days

This is another epic fundraiser to help Dr Helena Lee's work on the OLIVIA study, investigating the role of Oral Levodopa in Improving Visual development in Infants and young children with Albinism. Joe's youngest child was born with the condition and he is organising his challenge in great detail to obtain as much support as he can. Please read his personal story on his <u>fundraising page</u>.

#### **Gift of Sight Three Peaks Challenge 7th September**

A team of scientists, PhD students who work in our University's vision research team, together with staff and supporters, will be climbing Snowdon in Wales (1085m), Scafell Pike in England (978m) and Ben Nevis in Scotland (1345m) in just 24 hours. Now in training, many of them have been funded or supported in some way by Gift of Sight and this is their way of 'giving back'. We'd love you to help them reach their target of £5,000 and encourage them on their way through their <u>JustGiving page</u>.

#### Open Sight/Southampton Sight Eye Contact Exhibition 18th September 2024

Professor Lotery will be the keynote speaker at the event. Full details from Open Sight <a href="here">here</a>.

Contact: Ailsa Walter | T: 023 8059 9073 or Jennie Mugridge | T: 023 8059 5921

Email: info@giftofsight.org.uk Website: www.giftofsight.org.uk

To donate:

**Online**: visit **give.giftofsight.org.uk or** use your smartphone to **scan the QR code**:

By phone: call us on 023 8059 7239

By cheque: please post to Gift of Sight, Office of Development & Alumni Relations

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