

OCTOBER 2023 NEWSLETTER

Dear friends and supporters



Welcome to our final newsletter of 2023. It's been a good year for the research team and for all of us involved with Gift of Sight. So far our researchers have published more than 17 peer-reviewed papers, with more to come before the end of the year!

Our Pinnacle study of intermediate macular degeneration continues to give us new insights into what causes this disease to progress. 391 participants have completed one year of the study, 236 participants two years and 74 participants three years. We have observed that the photoreceptors are

frequently one of the first cells to be affected. This is a new finding and should help us target new therapies accordingly.

As part of this study we have also been using artificial intelligence to identify novel changes in the eye that we wouldn't otherwise think of as important. This work has identified some new early changes, or biomarkers, for age-related macular degeneration (AMD) and is now under review for publication. This project will run until 2025 and we hope the results will help us prioritise which patients would benefit from early interventions.

In September I presented some of our results from this study at a meeting that happens every four years in Baden-Baden, Germany. Because of the four-year cycle it is known as *'the AMD Olympics'*. Our results were well received and we have been asked to join forces with several other international studies so that the overall results will be more impactful.

We have also completed a clinical trial for a common inherited retinal disease called Stargardt. I'm pleased to report that the results from the study showed that Remofuscin, the drug tested, revealed reduced retinal thinning in patients treated. These results will hopefully lead to further development of this drug as a potential treatment for Stargardt disease. We continue with many other clinical trials for both dry and wet macular degeneration and I'm grateful to all the patients who take part in these studies.

Ailsa and Jennie have been busy promoting Gift of Sight and we are thrilled to hear of potential and definite fundraising support for 2024. We are looking forward to the annual Wade Lecture on the 13th November 2023, organised by the University's Faculty of Medicine. This year's speaker is Professor Sir Peng Tee Khaw, Director of the National Institute of Health Biomedical Research Centre at Moorfields Eye Hospital and the UCL Institute of Ophthalmology. Peng undertook his medical training at the University of Southampton and details of the Lecture are given overleaf.

Once again thank you for your invaluable support, which allows our work to progress more quickly.

With best wishes,

Andrew Loten

Andrew Lotery MD, FRCOphth Professor of Ophthalmology University of Southampton

The Gift of Sight Appeal is managed by the University of Southampton which is an 'Exempt Charity' (HMRC reference number X19140) under the terms of the Charities Act 2011.

Dr Helena Lee: Associate Professor of Ophthalmology

Funded by The Medical Research Council and Gift of Sight, my research is focused on developing disease specific therapies which target neuroplasticity. For example, using glasses and patching treatment to treat lazy eyes and improve vision in young children. These methods modulate abnormal retinal development in albinism, and other retinal developmental disorders, to help improve vision.



I previously identified a critical period of ongoing retinal development from birth up to 18 months of age in albinism which, if targeted with an

appropriate treatment, could improve retinal development and eyesight in infants and young children with this condition. This subsequently revealed that replacement of a chemical called Levodopa (L-DOPA), which is needed for normal eye development but is missing in albinism, can rescue abnormal retinal development and improve visual function in these patients. The next step from this work was to define the most appropriate drug dosages that could safely rescue retinal development and visual function in albinism, before moving on to clinical trials.

I am now delighted to report, that after several years of Covid-related delays, I have just published results which demonstrate that human equivalent doses of oral Levodopa (i.e. doses that are safely used to treat infants and young children with other conditions such as infantile dystonia and lazy eyes) can improve retinal development and visual function in a mouse model of human albinism. The full article can be found <u>here</u>. Having confirmed the doses of Levodopa that are required in order to be effective, I have now submitted my applications to the regulators for approval to proceed to the first clinical trial of the OLIVIA study (Oral Levodopa in Improving Visual development in Infants and young children with Albinism).

Until now, children with albinism have been deprived of an effective treatment. If successful, this study will completely change how children with albinism are treated. As this is the first trial of its kind to be designed it will also set an important precedent for the development and evaluation of new treatments for other eye diseases that affect children.

I recently walked 25.5 miles to complete the Rotary Test Way Walk with a group, fundraising for Gift of Sight. It wasn't an easy task, ploughing through deep mud at the end of a long and gruelling day and I was very grateful to everyone who supported us and cheered us over the finishing line.



Sarah MacDonald: PhD student

Supervised by Dr Helena Lee, I have just started the final year of my PhD investigating new treatments for children who have albinism. This lifelong condition affects the production of melanin, the pigment that colours skin, hair and eyes. The reduced amount of melanin can cause issues with a person's eyesight because it is involved in the development of the retina, the thin layer of cells at the back of the eye.

Previous research in our group has proved that L-DOPA, a drug that is usually used to treat Parkinson's Disease, could alter eye development if it was given at this critical time. This past year I have been focusing on quantifying the levels of different chemicals produced in the eye in response to low, medium and high doses of L-DOPA. This was to see if one of these chemicals could be turned into a new drug which may also work to improve eye development, giving us another exciting possibility for future treatments. Continued..

In my final year I will continue to investigate the most promising potential new drug focusing on any effects it may have on vision and eye development. It would be wonderful if I could end my study with a positive result that would lead to a new treatment. I am very grateful to the generous legacy donation to Gift of Sight that has funded my PhD studentship and given me the opportunity to carry out this vital research.

THANK YOU

Our warmest thanks to those of you who have taken the time to start new Direct Debits and also for popping cheques in the post to help support our scientists. It was lovely to receive a generous legacy of £20,000 from **Mrs Gladys Aspery**. As a patient at Southampton Eye Unit for many years, Gladys travelled to Southampton from the Isle of Wight to receive treatment for age-related macular degeneration. She was grateful to be part of an early clinical trial and her legacy will help our scientists continue their vital research projects.

Our heartfelt congratulations and thanks to **Ken and Marjorie Charman**, who celebrated their Platinum wedding anniversary on the 2nd July. They kindly raised the sum of £545 for our vision research team at their party in lieu of presents from their friends and family.

Thanks to Carol Gerrey and Kay Moran for organising the **Testvale Squares** 'Hoedown' at Foxlease in the New Forest, with their huge team of helpers. There were around 90 guests in the marquee and we all enjoyed an evening of dancing under instruction, with music provided in the interval by local singer/songwriter Harry Kemish. Ticket sales, a raffle and the sale of refreshments raised an amazing total of £1,329.75. So many of the guests were aware of our work and Carol gave a very emotive speech explaining the urgent need for eye research. Raffle prizes were provided by The Swan Lyndhurst, Furzey Gardens, Paws in the Forest, Paulton's Park, New Forest Aromatics, Setley Ridge Farm Shop, Pig Beer, Waitrose Portswood and others who brought gifts on the night. We're really grateful for this incredible help.

Ailsa enjoyed an afternoon tea with **The Foresters Friendly Society Court 2201** on the 24th September and was very pleased to receive a cheque for £539, which their members kindly raised for Gift of Sight. We have been in touch with this Court since 2009 and it's always lovely to reconnect! Thank you all for your ongoing support for our vision research team.



Professor Andrew Lotery was delighted to be with members of **RCSW 70 Club Supporters** on the 9th October at their Charity Quiz and Raffle evening. The 70 Club itself comprises of 350 people, some are Rotarians but others are friends and family members. They subscribe £1 per month into a lottery and half the money goes in prizes and half is donated to a charity chosen by the committee, often in conjunction with the Southampton Solent Rotary.

Andrew spoke to the guests, detailing how Gift of Sight funds support scientific projects which will lead to a greater understanding of eye diseases. David Chalmers, Chairman of 70 Club Supporters, presented a cheque for £1,500 representing raffle income and donations. Stuart Hill, President of Southampton Solent Rotary, presented a further cheque for £500, having chosen Gift of Sight as one of his three charities. We would like to thank all committee members and guests for their amazing support on the evening, and for sending us home with a cumulative gift of £2000.

It was lovely meet up with Neil Constantine-Smith, one of the Directors of **Specsavers, Lymington**, who have generously supported Gift of Sight since opening their branch in the town. They recently held a fundraising day to celebrate their 15th anniversary and a donation of £510 was presented to Ailsa. We have a very special relationship with this team and it's always great to be able to pass on updates of research, which have been helped by their generous fundraising.



Rotary Romsey Test Way Walk

Congratulations to Jennie Mugridge, Dr Helena Lee, Naomi Irving and Beccy Cowdrey, who all work at the University of Southampton. Our four fundraisers covered 25.5 miles of the Test Way, walking from St. Mary Bourne to Romsey to raise funds for Gift of Sight.

Parts of this walk are stunningly beautiful but there are a large number of stiles to negotiate at the end of the walk. The heavy rain that fell prior to the walk meant that the last field was a quagmire and everyone's walking boots were submerged in water. Despite aches and blisters the team were delighted to partake of a celebratory glass of fizz at the finishing point! Thank you for undertaking this challenge and raising £1400 to help our research!

FORTHCOMING EVENT

The Wade Lecture (Online) with Professor Sir Peng Tee Khaw 13th November 2023, 6.00pm—7.00pm

The Eyes are windows to our future : Research shaping the future of health

"Vision is our most precious sense. However, our visual system is complex and consumes huge amounts of energy (2% body weight up to 10+% of blood glucose). The structure and metabolic demands give rise to increasingly common age

related diseases such as macular degeneration or glaucoma. Research advances in cellular and molecular biology together with our ability to image the eye at cellular resolution is providing huge insights into both eye and systemic disorders such diabetes and neurodegeneration. Coupled with advances in technologies, the tantalising prospect of regenerative therapies to prevent and even reverse sight loss is here".

Specialising in adult and paediatric glaucoma, Sir Peng trained in Medicine at the University of Southampton. Please register to attend the Lecture online <u>here</u>, there is no charge involved. If you would like any further information or help please contact us using the details below.



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