

Dear friends and supporters,

It has been a busy few months! I have been travelling to conferences at home and abroad to share the results of our University of Southampton research - and to hear about new treatments and therapies being developed around the world. I was invited to speak at a national conference in Birmingham, and at international meetings in Denver in the USA and Tianjin in China.



At these meetings I presented our landmark PINNACLE study, which looks at age-related macular degeneration (AMD) at its intermediate stage - before serious sight loss has occurred. The study has identified early warning signs that tell us which patients are most likely to get worse. We believe this will help doctors monitor and care for patients much more effectively in the future. PINNACLE has already produced 16 scientific papers, with many more to come.

I also spoke about our study of central serous chorioretinopathy - a condition in which fluid collects under the retina at the back of the eye, blurring central vision. Our findings were published in 2020 in [The Lancet](#), one of the world's most respected medical journals, which changed how clinicians now treat patients with this condition. It was wonderful to hear that colleagues in the UK and overseas are now building on our results in their own research.

So far this year, our team has published 10 academic papers reinforcing the quality of our group's research studies. For me personally, this marks a milestone of being involved in more than 400 publications.

There is also exciting news about our younger researchers. Dr Rebecca Kaye (pictured above), a former PhD student of mine whose studies were supported by Gift of Sight, has been awarded a highly competitive academic clinical lectureship funded by the National Institute for Health and Care Research (NIHR). These prestigious posts allow doctors to combine caring for patients with carrying out research, and this will give Rebecca the chance to develop her own research ideas and become an independent scientist in her own right.

Thanks to a very generous gift left in a supporter's Will, we can offer Charlie Ellis a further two years in our research team. Charlie, who is supervised by Dr Arjuna Ratnayaka, is nearing completion of his PhD. His work explores how waste products build up in cells at the back of the eye; a process thought to play an important part in sight-threatening diseases such as AMD. This funding will set him firmly on his scientific career and enable him to gather the evidence he needs to apply for major grants from leading research funders. A very exciting start to 2026!

I really enjoyed meeting guests at Little Court in June and I am hugely grateful to those of you who have been fundraising for us recently. My heartfelt thanks to you all for your continuing support for our vital research.



Andrew Lotery MD, FRCOphth
Professor of Ophthalmology
University of Southampton

Associate Professor Dr Helena Lee

Thanks to the continued support of Gift of Sight, our research programme into albinism is making exciting progress on several fronts. One of our major goals is to develop the first treatments capable of improving visual development in children with albinism. This work spans laboratory science, clinical research and international collaboration.



A particular highlight this year was attending the Medical Research Foundation Child & Adolescent Health Networking event with my postdoctoral fellow, Sarah MacDonald, where we shared two strands of our ongoing work. Sarah presented our studies investigating pigment epithelium-derived factor (PEDF) as a potential treatment for albinism, building on previous discoveries from our group that identified important pathways involved in retinal development in the condition. We also shared results from our large-scale drug screening programme, examining hundreds of existing medicines to identify candidates that could be repurposed to improve vision in albinism. Because these drugs have already undergone extensive safety testing, successful candidates could potentially reach patients much more quickly than entirely new medicines.

We have also recently celebrated the publication of clinical research led by our orthoptists Jeremy Bradshaw and Megan Evans in [Investigative Ophthalmology & Visual Science \(IOVS\)](#). This study examined the use of yoked prism glasses in improving visual function and quality of life in people affected by nystagmus. The publication adds to a growing body of evidence aimed at improving the care available to patients today while we work towards future treatments.

Alongside these developments, we continue to make progress towards launching the OLIVIA trial (Oral Levodopa in Improving Visual Development in Infants and Young Children with Albinism). This first-in-human study will investigate whether oral levodopa, a medicine already used safely in children for other conditions, can improve retinal development during the critical early stages of life (if administered between 3 and 18 months of age). Significant work is ongoing with regulatory approvals, study set-up and site preparation to ensure the trial can be delivered safely and successfully.

We are enormously grateful to our Gift of Sight supporters whose generosity continues to make this research possible and helps bring new treatments for albinism closer to reality.

Associate Professor Dr Jay Self

We are making real progress in improving diagnosis, treatment, and wellbeing for children affected by albinism, nystagmus, amblyopia (lazy eye) and other visual disorders. Over the past year, our team has continued to develop nationally adopted diagnostic pathways for albinism and childhood nystagmus, advance new technologies that improve access to specialist testing, and progress exciting translational research aimed at developing the first medical treatments for visual impairment in albinism. As mentioned by Helena, we are also preparing to launch the OLIVIA trial, which has taken years of laboratory and clinical research.



Alongside these projects, we are developing a new generation of “Games for Health” therapies designed to improve treatment adherence and visual outcomes for children. These include both parent-facing and child-facing apps for amblyopia and nystagmus, translating research findings into practical tools that families can use at home. We also continue to work with patients and families through [Albinism Mythbusters](#), and these educational resources now reach more than 1.5 million people worldwide.

Your generous philanthropic donations have helped us undertake laboratory-based tests on modified human cells to investigate various FDA-approved drugs to determine which would be the best one to treat albinism. Our leading candidate drug has been patented by the University of Southampton (UoS) to protect the intellectual property and facilitate potential future investment by pharmaceutical companies. We are currently working with UoS-affiliated partners on a commercialisation plan to attract funding for the costly clinical trials that will follow once our laboratory work is complete. We have a significant research paper being considered for publication and we expect a result shortly.

Dr Ellie Keeling, who has undertaken all the above activity, is currently on maternity leave and her work is being overseen by a colleague during this time. A senior laboratory technician has been recruited, to provide support for both our human stem cell lab team and Ellie on her return. I would like to add my thanks to Helena's for your continuing generous support for our work.

However, to maintain the momentum across our group, we are seeking support for several exciting new initiatives and looking to raise significant funds, each in the region of £150,000. We really need to recruit a PhD student to complete the development and evaluation of our amblyopia and nystagmus digital health apps, and a post-doctoral researcher to expand our successful drug-discovery programme from OCA1 to OCA2, the most common form of albinism globally. In addition, a joint PhD studentship with the Department of Chemistry would enable us to develop and optimise promising new drug candidates arising from our albinism research. Finally, £50,000 would provide pump-priming funding for orthoptist and researcher Dan Osborne, featured below, enabling him to continue his innovative work to improve outcomes for children with amblyopia.

Daniel Osborne, Research Orthoptist

Dan began his career as an orthoptist in Southampton Eye Unit in 2015, developing a passion for understanding the human aspects and emotional complexities of paediatric eye care, which laid the foundation for his clinical and academic research.



Over the years, he was awarded a series of competitive posts, including an NIHR Pre-Doctoral Clinical Academic Fellowship (PCAF). These posts led him to undertake formal research training, gain experience and develop a competitive PhD proposal while continuing his clinical development. This proved to be time well spent, as he became the first Allied Health Professional (AHP) to be awarded a Wellcome PhD Fellowship.

With his PhD completed, Dan now works two days a week in specialist electrophysiology in Southampton and three days a week at Moorfields UCL, where he will be teaching on the orthoptics master's course. He is currently seeking major grant funding to continue his research.

Albinism Fellowship Family Fun Day - 9th May 2026

We were delighted to be with members of [the Albinism Fellowship](#) at their Family Fun Day in Eastleigh. This amazing event brought families together to share experiences and learn more about albinism through insightful talks from Drs Jay Self and Helena Lee, Dan Osborne, and Paralympian Adam Knott.



Kristina Rose, from the Albinism Fellowship, is training to cycle on a tandem from London to Brighton in September, piloted by her friend Tegan. Kristina's visual impairment makes this challenge even more remarkable, and Dan Osborne will ride alongside. This epic venture is raising funds jointly for Gift of Sight and the Albinism Fellowship. Find out more via [Kristina's JustGiving Page](#).

THANK YOU TO OUR WONDERFUL FUNDRAISERS



Thank you to everyone who braved the chilly weather to join us at our Little Court Garden Party in June. It was wonderful to have so many guests with us enjoying this beautiful garden. We would also like to thank Louis Pommery at Pinglestone Estate, Leckford Farm, Five Boroughs Pizza, and Chalk Stream Trout for donating generous raffle prizes. Our heartfelt thanks go to **Mrs Patricia Elkington** for hosting this fantastic event, which raised a fabulous **£2,000**.



Michael Schruyers, together with his friends and family, raised an amazing **£1,500** to support our albinism research. Inspired by a friend's daughter, Gracie, they climbed seven mountains across England and Wales, while Michael also organised three fundraising darts events. Thank you to everyone involved!

Congratulations to **Michael Hiden** on running four miles every four hours for 48 hours. This exhausting challenge was motivated by his partner Jenny's experience of sight loss, and he raised an incredible **£1,421** to help our research.



Thanks to **Cathy Murphy**, a Clinical Nurse in Ophthalmology, who stepped into the boxing ring for the first time to raise funds for Gift of Sight. Her bravery and determination helped raise a brilliant **£400**.

Wishing **Nicholas Davidson** luck on walking the 25km Thames Bridges Trek on 12 September, crossing 16 of London's bridges. If you'd like to support him, please quote 'Nicholas Trek' when donating online.

UPCOMING EVENTS IN 2026: Full details at www.giftofsight.org.uk/events



24 September 2026 - Quiz Night in Lymington. Tickets £20 per person including supper
Put your knowledge to the test at Lymington Town Sailing Club with our quiz master, Specsavers' own Neil Constantine-Smith. Please come on your own or as part of a team (6-8 per table) and enjoy a one-course supper before the quiz begins. Professor Andrew Lotery will give a short update on recent developments in eye research. There will also be a raffle, with drinks available from the bar. **Booking link:** give.giftofsight.org.uk/quiz



SAVE THE DATE! 16 December 2026 - Christmas in the Chapel

Join us for a traditional carol concert at Winchester College Chapel with music directed by Andrew Hayman. Booking details will be on our website soon!

Can you help? If you know a local business that might like to support our events - through sponsorship or by donating a raffle prize, we'd love to hear from you. We're always grateful for your introductions!

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

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

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