

Dear Friends and supporters

I am delighted that our research studies are slowly returning to some sort of 'normal'. Our scientists are now able to work in the laboratories, although restricted to some degree to keep them socially distanced and safe. Patients taking part in our clinical trials programme are now being recalled so that we can continue with our vital studies.



Our Wellcome Trust funded study of early age-related macular degeneration (AMD) has restarted and we are keen to recruit patients with early stage AMD who would be willing to be seen in Southampton 3 times a year for 3 years. This study will help us understand what causes patients to progress to the more serious late stages of the disease. If you are interested in knowing more about the study and would consider participating please contact us at EyeResearch@uhs.nhs.uk or on 023 8120 4606.

Due to the pandemic we have endured serious disruption to our academic work with donations being impacted both to external funding bodies and to Gift of Sight. However, a very generous and unexpected legacy of £30,000 was received at the end of July. Legacy bequests are such a personal gift and I would like to thank all the people who intend to help our work in this way. In many instances your intentions are made known to us only when we receive a bequest from your Solicitor. Any sum, however large or small, make a tremendous impact on what we are able to achieve. Thank you.

Despite the challenges of COVID-19 we have managed to publish 18 papers from January to August, ie more than 2 per month. To put this in perspective the Government requires academic researchers to produce 4 papers in 4 years as part of their review of Universities so, by this measure, we are being very productive. One of our recent publications was a collaboration with scientists in Finland using patient stem cells to model a retinal disease called Sorsby Fundus Dystrophy. This was published in the prestigious Journal of Pathology and Dr Jenny Dewing has reported on this study overleaf.

I am keen to see our scientists develop human stem cell work further, for example to model diseases such as AMD in patient stem cells. Current laboratory space is small and a larger one has been identified within the hospital which will accommodate more research staff. A very supportive donor has generously agreed to pay the cost of refurbishing this space to the exacting specifications required, he will also assist with funding the area for three years. I am delighted, and so grateful, that Gift of Sight is the recipient of such a wonderful act of philanthropy in these difficult times.

My thanks to you all, as always, for your interest in our vital research and I trust you are all keeping safe and well.

With very best wishes,

Andrew Lotery MD, FRCOphth
Professor of Ophthalmology
University of Southampton

Dr Helena Lee: MRC Clinician Scientist & Associate Professor of Ophthalmology



Helena has been awarded the prestigious Squint Forum Prize from the Royal Society of Medicine for her innovative research in albinism. The Prize, awarded annually, recognises high quality research performed in the fields of binocular vision and eye movement. She will present her research in December at the Royal Society of Medicine annual Squint Forum meeting, taking place online this year. Her research, funded by The Medical Research Council and Gift of Sight, is focused on developing disease specific therapies which target neuroplasticity to modulate abnormal retinal development in albinism and other retinal developmental disorders, in order to improve vision.

She has found that a chemical called Levodopa is needed for normal eye development but is missing in the eyes of children with albinism. Having recently demonstrated proof of concept for oral Levodopa in improving retinal development and visual function in a mouse model of human albinism, she is now beginning work on the OLIVIA trial (Oral Levodopa in Improving Visual development in Infants and young children with Albinism). If successful, this study will completely change how children with albinism are treated. It will also set an important precedent for the development of new treatments for other eye diseases that affect children.

The coronavirus epidemic in the UK has meant that up to 5,000 children's eye appointments have been cancelled, which means many patients are missing out on time-critical treatment for routine, treatable disease such as lazy eye (amblyopia). Early Career Researcher and 2019 Gift of Sight Clinical Research Award winner, Daniel Osborne, has been awarded funding from Southampton Hospitals Charity and the National Institute for Health Research (NIHR) to set up a study that aims to develop new ways of testing children's eyes without the need for them to attend hospital clinics.

The CHEETAH (stands for, CHildren's Eye Examination and Testing At Home) Study is currently recruiting paediatric patients to have their eyes tested using a novel, iPad-based method, which could be performed easily at home without being physically present in hospital. We hope the new testing method will provide our patients with a practical option to have an eye assessment during the time they cannot be seen in hospital. In the longer term we hope that the home-based testing method will provide patients and their parents with more control and information about their condition. The method may provide patients with real-time information about their disease severity and inform them of progress with the treatment they are having. The CHEETAH Study has the immediate potential to improve care for patients during coronavirus but also to improve our current best-practice so that, after coronavirus, we can look after patients better than we could before the pandemic.

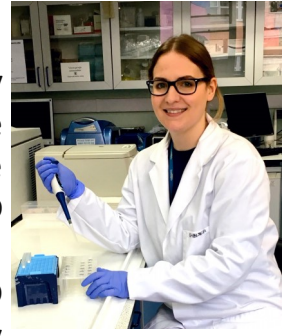
Daniel Osborne: Clinical Research Orthoptist

The postponement of appointments at eye clinics throughout the UK is a particular problem for children having eye patching therapy for amblyopia. This is a common condition, with approximately 5% of all children affected. Undertaking visual acuity assessments at home may help increase a patient's adherence to therapy and help improve visual acuity outcomes. This will also benefit the NHS clinical service, with the potential reduction in numbers of outpatient appointments for these children.

Phase 1 of the Cheetah study will involve visual acuity measurements being taken in the outpatient clinic as per standard of care. Parents or carers will use an iPad to test visual acuity at the same visit before starting to test at home. My thanks to Gift of Sight donors who have helped purchase iPads for this trial.

Dr Jenny Dewing: Postdoctoral Research Fellow

I joined Dr Arjuna Ratnayaka's group as a Postdoctoral Research Fellow in January 2018. The aim of my research is to understand the molecular mechanisms of the rare, genetic eye disease Sorsby Fundus Dystrophy (SFD). SFD is very similar to the more common age-related macular degeneration (AMD); however, the onset of SFD occurs much earlier, with initial symptoms in patients as young as 30 years of age. Damage to the light-sensing photoreceptors in the macula of the retina in SFD patients causes progressive loss of central vision, making it difficult to do everyday tasks like driving, reading and writing. SFD is an inherited disorder caused by mutations in the gene TIMP3, which has a number of important roles, including modifying the environment outside cells, controlling inflammation and regulating blood vessel growth : essential mechanisms in maintaining healthy retinas. At the beginning of the year, we published a review article in the journal 'Cells' discussing the roles of TIMP3 in both the retina and brain, and how, in addition to SFD, TIMP3 dysregulation is implicated in AMD and Alzheimer's disease.



We also recently published an exciting research article in the 'Journal of Pathology'. In this study we used stem cells from SFD patients from Southampton to generate cells of the retina, allowing us to model the disease 'in a dish'. In collaboration with scientists in Finland, we were able to show that retinal cells made from SFD patient stem cells contain much higher levels of TIMP3 protein compared to controls, suggesting that the mutant TIMP3 protein is not being cleared properly from the retina. It has previously been suggested that mutations in TIMP3 could prevent the protein from working properly; however, we showed that mutant TIMP3 proteins remain active in retinal cells, suggesting that SFD is caused by there being too much functional TIMP3, rather than an absence or deficiency of TIMP3. Based on these exciting findings we are now hoping to continue our research to investigate why mutant TIMP3 is accumulating in the retinas of SFD patients and how we can prevent this.

Sorsby Fundus Dystrophy patients: Emma Roach and Claire Street

Sisters, Emma and Claire, both have Sorsby Fundus Dystrophy (SFD). Their Father lost his central vision within twelve months of noticing the first symptoms and, at the time of his diagnosis in 1990, there was no treatment available for this disease. Claire was diagnosed with SFD in 2006, although by the time she was referred to Southampton she had lost much of her central vision in one eye. In 2007 Professor Lotery organised genetic testing in Southampton for the family and when Emma's vision started worsening in 2012 her treatment was able to start quickly.



Claire attends Southampton Eye Unit every four weeks for eye injections, whilst Emma is on an eight weekly rotation, which keeps their vision stable. Their Mother Val provides great support driving them to clinics and they are grateful that their treatment is available through the NHS. Both can still see some images on television, walk during the day and can read using a screen. On the 'down side' neither are able to drive and find it hard to read letters and bills with small writing. Thankfully computer technology, visual aids and requesting help from their families means there is always a way to cope.

The family donated skin samples, mentioned above by Dr Dewing, which have been invaluable to our scientists, allowing different types of laboratory experiments to be undertaken than could be made with just a blood sample. Claire and Emma are hopeful that a less invasive type of treatment may be available in the future but are thankful for the care and commitment they experience from the clinical team in Southampton Eye Unit. The whole family follow our scientific research, were delighted to see their cells in the laboratory and are great supporters of, and advocates for, Gift of Sight.

The University of Southampton is a member of the Russell Group of Universities which are globally renowned for their contribution to research, nurturing innovation, creating jobs and changing lives for the better across the UK and around the world. Your generous support for Gift of Sight has helped the vision science research group grow year on year and we now have a well-established team of scientists, investigating diseases which affect patients of all ages and giving hope of future treatments to those who have to cope with progressive sight loss.

Our research teams have survived the recent difficulties caused by the coronavirus pandemic by working from home, using computer technology to attend meetings and picking up the telephone! Thankfully they are now able to continue their laboratory work, as mentioned by Professor Lotery. This has not been without cost as cells were lost during the lockdown period, grant funding has been hard to come by and the return to a slightly more normal way of working will take time and effort to make sure that everyone stays safe.

Given these difficult circumstances we are delighted that Dr Arjuna Ratnayaka has received academic grant funding of £100k from the Macular Society to recruit a PhD student to further his research into AMD. His team are achieving tremendous results and the discoveries being made are helping us to more fully understand some of the many reasons why this complicated and debilitating retinal disease affects such a large number of people.

Sadly our annual Carol Concert in Romsey Abbey has been cancelled. This will come as no surprise, given the uncertainty of how the coronavirus pandemic will pan out over the next few months. This is an event that we all look forward to and, in conversation with Ally Allfrey who leads our wonderful event committee, it was agreed that an on-line event wasn't an alternative as the costs of producing the Concert would have been high. David Clegg, who organises the musical programme for us each year and the professional singers of Aurum Vocale share our disappointment. Whilst many of their bookings have been cancelled they were delighted to be the chosen choir for the VJ Event celebrations live from the National Memorial Arboretum on BBC1 in August. If you were watching and have attended our Concerts in the past you will probably have recognised some familiar faces! We all hope for a brighter performing year for them in 2021 and they send their very warmest wishes to our Gift of Sight supporters. We hope that you may feel able to send a donation to help us regain some of the lost income due to this cancellation using the methods below. Our next Carol Concert is planned to take place on Tuesday, 14 December 2021.

We hope to be able to see some of you earlier next year if we are able to organise some fundraising events..

Please read our Privacy statement at <https://www.giftofsight.org.uk/gift-sight-privacy-statement>

Contact: Ailsa Walter | T: **023 8059 9073** Calls will be forwarded to our mobile phone whilst working from home | Email: info@giftofsight.org.uk | Web: www.giftofsight.org.uk

To donate: **By card**—T: **023 8059 7239** | **On-line:** <https://donate.giftofsight.org.uk/>
By cheque: Please post to **Gift of Sight, Office of Development and Alumni Relations, Building 37, Highfield, Southampton, SO17 1BJ**

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