national eye
RESEARCH CENTRE

Together, we can beat sight loss forever.

Annual Report 2018-19

www.nercuk.org

Who we are

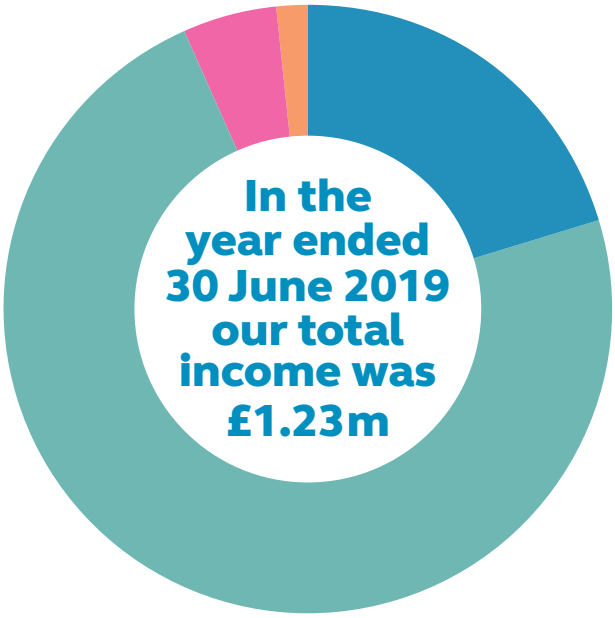
We are a community of donors, volunteers, researchers, healthcare professionals, and fundraisers working together towards our common goal of beating sight loss forever.

What we do

We fund pioneering research into the causes of eye disease to develop better prevention methods and more effective treatments for children and adults.

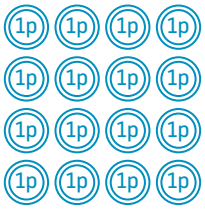
Together, we can beat sight loss forever.

Our finances



- Donations: **£251,000**
- Legacies: **£892,000**
- Investments: **£65,000**
- Gifts in kind: **£24,000**

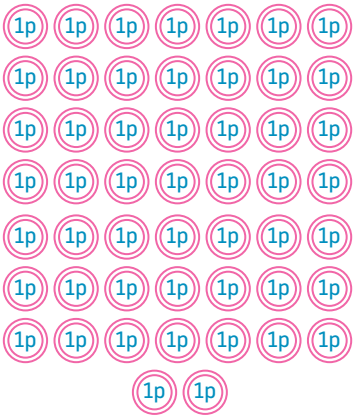
- Research grants: **£644,000**
- Fundraising: **£130,000**
- Charity management and Governance: **£98,000**



It cost us 16p to raise £1*

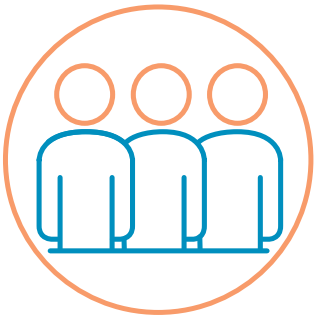
* Our 5-year aggregate is 30p:£1. This is due to volatility nature of legacy gifts which account for a significant part of our income.

We spent 51p of every £1 on funding research*



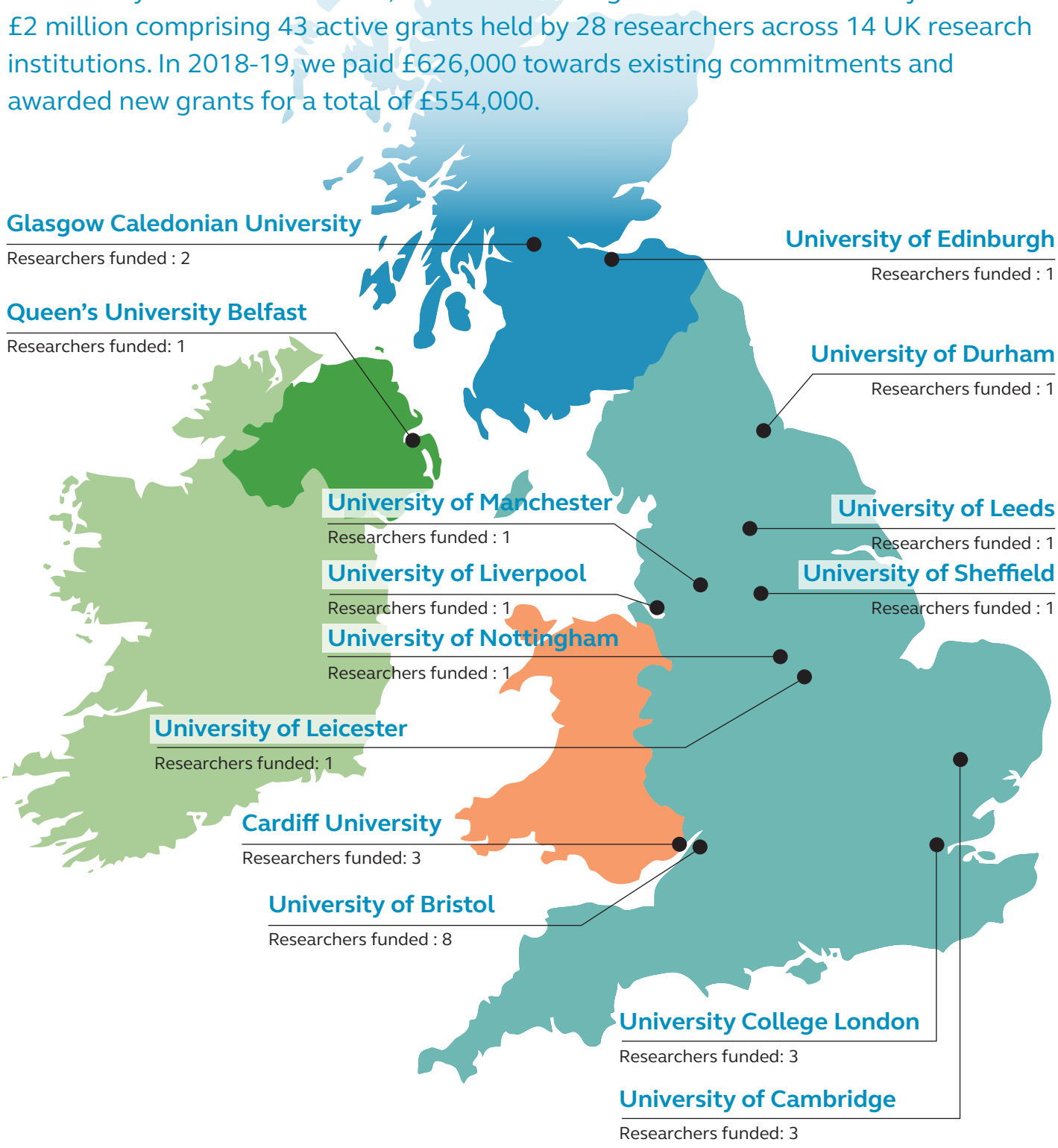
* We have also designated £400,000 to an ambitious research campaign we will launch in 2020.

Number of employees: 3

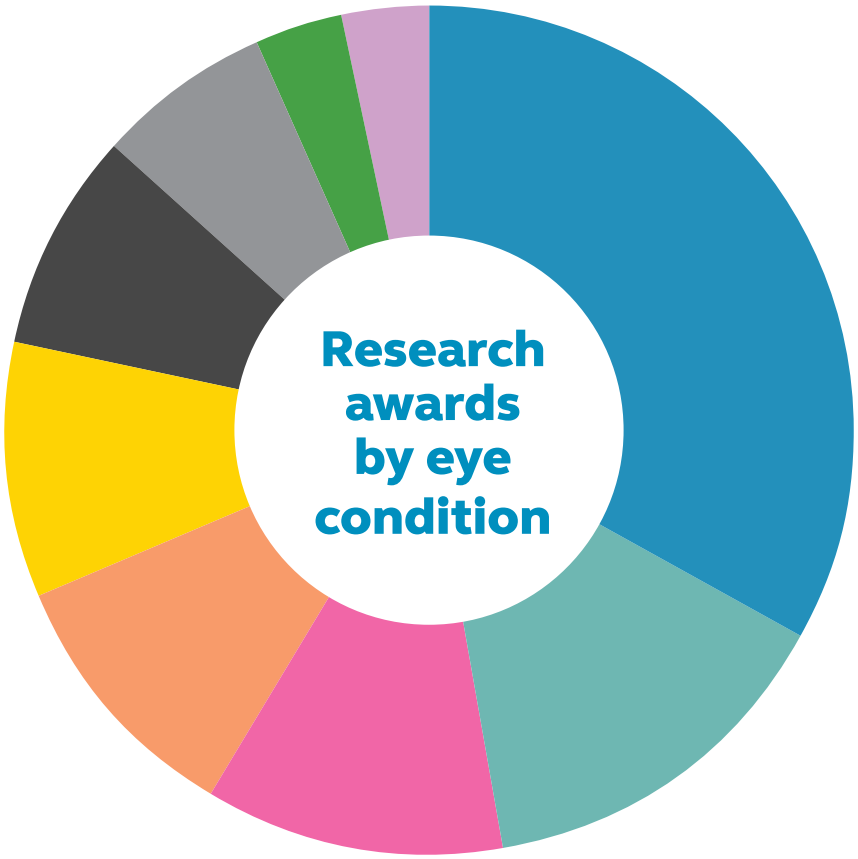


Our research

Our grants range from travel grants to proof of concept projects, to PhD studentships and postdoctoral major research projects. All of our grants are awarded through open competition. Applications are assessed in a two-stage process by an independent Scientific Advisory Committee and are also peer-reviewed by relevant experts in the eye research sector, chosen among the international research community. As at 30 June 2019, our active funding commitments totalled just over £2 million comprising 43 active grants held by 28 researchers across 14 UK research institutions. In 2018-19, we paid £626,000 towards existing commitments and awarded new grants for a total of £554,000.



Research by focus



- Inflammatory Eye Disease
- Age-related Macular Degeneration
- Inherited Retinal Dystrophies
- Gene Therapy
- Glaucoma
- Diabetic Retinopathy
- Children's eye conditions
- Corneal dystrophies
- Cataracts

The cure for sight loss? You are it.

As I reflect on the last 12 months, I do so with immense gratitude for your help, support, advice, encouragement and vote of confidence along the way. I have been buoyed by your loyalty to our vision, and by your enthusiasm for working together to achieve even more towards our shared goal of beating sight loss forever.

Over the last year, you have made gifts, you have run, you have baked, and you have honoured the memory of a much missed loved one. Some of you have pledged to support us in the future with a gift in your Will, and some have made a regular commitment to eye research now. We were humbled to receive gifts in Wills from donors whom we had not had the chance to know before their donations arrived, so we thank them here, wholeheartedly, for their help.

In the past few months, I have been thrilled to meet as many of you as I could and hear your thoughts, hopes

and fears for the future. Whether you are living with an eye condition right now, or are supporting a loved one with sight loss, or are dedicated to find new eye disease treatments for the good of society, each and every one of you believes we can and must do more to advance progress. You know that, together, we can create the change that is needed.

> **Believe in your ability to create change: it is limitless.**

The National Eye Research Centre belongs to all of you, our supporters. You each provide an indispensable contribution and your views will help to shape our future strategic direction. Thank you to all those who have already shared their feedback, and we look forward to hearing your ideas as we consult with you all further over the next few months. Believe in your ability to create change: it is limitless.

Laura Serratrice CEO

Staying the course

Over the last three decades, thanks to our donors, we have played a key part in one of the most impactful eye research success stories of our time: the establishment of a national corneal transplant service. Professor John Armitage's research has been instrumental in making this happen.

In 2019, Professor John Armitage was awarded an OBE for his services to corneal transplant. To hear him tell it, his whole research career has been based on luck. But it doesn't take long to guess that behind his quiet modesty lies a steely determination to solve a problem.

After completing a PhD in cardiac cryopreservation and following research posts in Cambridge, UK and the USA, a serendipitous phone call in October 1984 took John to Bristol, to meet Professor David Easty, the then Head of Ophthalmology, and Ben Bradley, the then Medical Director of the UK Transplant Service.

John recalls being intrigued by the plans for an MRC funded project on corneal cryo preservation together with the ambition to set up an eye bank. In the mid-1980s, corneal transplants were made possible either by local tissue donors, or by corneas preserved at Moorfields Eye Hospital or at the Queen Victoria Hospital in East Grinstead.

> **"Above all, I must acknowledge the thoughtfulness and generosity of the families of eye donors, without whom tissue and organ transplantation would not be possible.**

Until then, corneas could be stored only up to 24 to 48 hours, which meant that corneal grafts had to be emergency operations, often with patients spending days in hospital waiting for a cornea.

Over the next 30 years, John's research would make contributions that enabled corneas to be stored up to four weeks. This advancement led to the eventual creation of a national eye bank and transplant service, in collaboration with the Manchester Eye Bank, which the NHS Blood and Transplant Service fully took over in 2015.

Today, 4,000 corneal transplants are performed every year as elective, outpatient surgeries. In total, over 80,000 patients have benefited from these advancements over the last three decades, and transplant success rates are improving all the time.

> **“… seeing that what you’ve done has ended up benefiting patients, ended up helping people – I can’t put it better than that.**

When I ask him, of course, John says he can’t really take all the credit.

He says he just connected the dots; he was lucky to be in the right place at the right time. But when I press him, he concedes that, yes, you have to be able to do something with all that luck.

As John sees it, the true key to problem solving is collaboration, it’s not giving up when things don’t work out, and instead taking the opportunity to try another way to find a solution. Colleagues in Minneapolis, Aarhus, and Amsterdam paved the way to John’s optimisation of the cornea storage method – through organ culture – and he’s quick to give them the credit they deserve, and so he should.

The greatest benefits of collaboration in research are gained through working with colleagues who have complementary skills and backgrounds. For John, this has meant combining his scientific expertise on tissue and cell preservation with the clinical applications of that knowledge in order to benefit patients.

Today, transplant techniques and efficacy are improving all the time making visual rehabilitation faster – from a couple of years to a couple of months – and longer lasting, too.

So, what have I learnt? That when it comes to problem solving in medical research, there are many parts to the whole. That things work out when each of us – donors, researchers, and fundraisers – brings their own particular contribution and joins forces with those who can do what we can’t. That there are always bumps along the road, but the key is staying the course, not losing focus on the goal. That the road is often a long and arduous one, but every new treatment has been on the same journey, and those who didn’t give up made it happen.

Treatments like corneal transplants are available in our clinics today only thanks to decades of research investment, but there is so much more to be done. With your gift, you can be part of future success stories and help to beat sight loss forever. Thank you so much.

Latest funded research

Predicting risk of developing retinopathy of prematurity in babies

Professor Irene Gottlob, University of Leicester

Retinopathy of prematurity (ROP) is one of the most common avoidable causes of childhood blindness globally. If detected early, it can be treated but the currently available screening process is inefficient, lengthy, distressing for babies, and costly. This project is assessing whether a new, non-invasive screening approach can more confidently predict which babies born with ROP will need treatment (typically fewer than 10%).

Are insulin signalling and myopia related?

Dr Denize Atan, University of Bristol

People with severe myopia (short-sightedness) are at significantly higher risk of developing sight-threatening conditions such as retinal detachment and macular degeneration in later life, and their risk of developing glaucoma or cataract is comparable with the risk of stroke from smoking over 20 cigarettes a day. It is estimated that, globally, almost 1 billion people will be classed as severely myopic by 2050 and recent studies indicate that myopic macular degeneration is already one of the three leading causes of blindness worldwide. This research is hoping to increase our knowledge and our understanding about how myopia develops in children an how its onset and progression might be prevented.

New drugs to treat mitochondrial optic neuropathies

Professor Marcela Votruba, Cardiff University

Mitochondrial optic neuropathies are an important group of disorders that affect at least 1 in 10,000 individuals in the UK. They are characterised by the malfunction of mitochondria, small organelles present in our cells. Leber Hereditary Optic Neuropathy (LHON) and Autosomal-Dominant Optic Atrophy (ADOA) are the two most common mitochondrial optic neuropathies. These inherited conditions lead to progressive, debilitating loss of vision, severely impacting on quality of life and

independence. The cause is a genetic mutation that disrupts the function of retinal ganglion cells interrupting the normal communication between the retina, the optic nerve, and the brain. The goal of this research is to develop sustained release formulations for new drugs that prevent retinal ganglion cell loss with the hope that these could eventually lead to clinical trials.

Regenerative therapies to treat retinal dystrophies

Dr Rachel Pearson, University College London

Retinal dystrophies such as retinitis pigmentosa, macular degeneration, and diabetic retinopathy are characterised by photoreceptor degeneration and are a leading cause of untreatable blindness in the industrialised world.

Photoreceptors are light-sensing neurons located in the retina, at the back of the eye. These are highly specialised cells that are prone to damage and which, once lost, cannot be replaced. Currently, there are few effective therapies and the majority attempt to slow down vision loss, not recuperate vision. This research is testing the attractive, but unproven, alternative to unlock the potential for making the retina repair itself. The hypothesis is that cells in the retinas which are undergoing progressive photoreceptor loss have the capacity to regenerate themselves. If successful, this research may pave the way for retinal regeneration in humans with the goal of preventing blindness.

Identifying risk factors for retinal detachment

Dr Véronique Vitart, University of Edinburgh

Retinal detachment is a serious common condition that can lead to blindness, if left untreated. It occurs more frequently in people with myopia (short-sightedness).

Researchers at the University of Edinburgh were the first to discover that some myopia-associated mutations within and close to a gene called BMP3 increase the risk of retinal detachment. This research project focuses on the role of BMP3 in the eye. An important part of developing a new drug treatments is understanding the biological pathways, in other words the series of actions among molecules in a cell that leads to a certain product or a change in the cell. Identifying what genes, proteins and other molecules are involved in a biological pathway can provide clues about what goes wrong when a disease strikes.

Drugs already exist which can modulate the BMP pathway, which is promising for the development of therapies. However, this pathway is involved in many different processes and other diseases, so a better understanding of its role specifically in the eye is needed.

Are there environmental triggers associated with the onset of AMD?

Professor Glen Jeffery, University College London

To date, little attention has been paid to the role of the environment and its pathogens as potential drivers of Age-related Macular Degeneration (AMD). In part, this is because disease development is slow, and human environmental exposure is complex and varied. This project will assess a disease model of AMD and test its potential AMD onset response to being exposed to pathogens. This may have significant consequences for patients if reduced pathogen exposure, via flu inoculation for instance, were found to have a positive impact on reducing the potential for the development of AMD.

Seeking new treatment targets for uveitis

Dr Lindsay Nicholson, University of Bristol

Most cases of non-infectious uveitis – a type of inflammatory eye disease – are caused by the immune system becoming overactive and mistakenly attacking the eye, leading to retinal damage.

Disease causing inflammation arises from a mixture of specific and non-specific cell types. The specific cells target and co-ordinate the disease, and the non-specific cells amplify the process and promote tissue destruction. This project will seek to better understand this process to pave the way to the ideal immunotherapy – one which shuts down the specific cells.

The research will seek to find a signal that identifies only the specific cells based on preliminary laboratory data identifying markers for these. If successful, this would be a unique approach to treating disease by selectively eliminating only disease-causing lymphocytes.

Profiling immune cells during regional ocular inflammation

Dr David Copland, University of Bristol

Research led by Dr Copland has highlighted how different sets of genes are altered in different types of cell during inflammation. However, focusing on the whole retinal tissue does not allow investigators to distinguish the differences between the inflammatory and healthy areas that are seen clinically across the retina. This project therefore seeks to refine this approach by combining clinical imaging to first identify, and then biopsy specific regions of active inflammation from across a single retina to understand the differences in gene expression.

This research will produce the first comprehensive assessment of molecular disease pathways that are expressed by specific populations of immune cells found in the retina, and how these influence the distinct disease patterns.

Without gifts in Wills, most of our research would not happen

Over the last five years, we have been able to commit £3.3 million to new research projects seeking new understanding of eye disease in children and adults. For the most part, this crucial investment was only possible thanks to the generosity of over 70 donors who left gifts in their Wills totalling over £2.7 million, ranging from £100 to over £400,000. Each one was vital in enabling progress.

Without these gifts, we would have had to reject 4 in 5 of our research projects and, with the woeful lack of funding available for eye research, it is very likely that these projects would not have happened at all. So, these gifts have played an even more pivotal role in advancing our knowledge of eye disease and seeking new ways to beating sight loss.

It may surprise you to learn that less than 2% of all medical research funding in the UK is allocated to eye research. And yet, over 2 million people are already living with sight loss today, with that number set to double by 2050 if we do not invest more into eye research over the next 30 years.

The need to grow investment in eye research is unquestionable. If the time is ever right for you to consider supporting us with a gift in your Will – thank you. Every gift makes a terrific difference regardless of its size. A gift of even 1% of your estate, so those closest to you get 99%, is truly invaluable.

Leaving a gift in your Will could not be simpler. All you need to give to your professional adviser is our charity number: 1156134. And, if you would like your legacy used for a specific area of eye research, we would be delighted to discuss your wishes with you. Just call us on 0117 325 7757 or email us at legacies@nercuk.org. Thank you.

> **“With a gift in your Will, you can help others to see hope, and a future without sight loss.**

Thank you

Donations were received in memory of:

Mrs Shoushan Alexander, Mrs Joan Blake, Mr Royston Bird, Mr A R Boult, Mrs Kitty Cousens, Mr Desmond Carter, Mr Sidney Cole, Mr Colin Cushing, Ms Isabella Dunn, Mr W Earle, Mrs Margaret Edenborough, Mr Michael Futcher, Mrs Brenda Hayes, Mr Robert Hooper, Mr Russell Hudson, Mrs Humphry, Mr Derek Klemperer, Mrs Norma Lorton, Mrs Jean McGrath, Ms Audrey Mears, Mr Paul Monk, Mrs Eileen Obsorne, Mrs Winifred Pike, Mrs Ethel Pybus, Mrs Betty Rosbotham, Mr Douglas Russell, Mr James Harold Scrase, Mrs Marjorie Rockliffe, Mr Philip Tatlow, Mr Robert Washburn, Mr Dennis Williams.

We are grateful for legacies from:

Miss Elizabeth Barrie, Ms Gertrude Bartlett, Mr Martin Broker, Miss Elaine Brumstead, Ms Dorothy Burns, Mrs Gladys Gordon-Crofts, Mrs Pauline Gyles, Mr Alfred Hannah, Miss Mary Harmer, Mrs Lamplough, Mr Peter Mann, Mrs Jill McLeod, Mr Robin Mills, Mr Thomas Pearce, Mr Spencer John Robertson, Mrs Margaret Silvester, Mr Richard Wyld.

Thank you to donors who made gifts in excess of £500:

H B Allen Charitable Trust; The William Allen Young Charitable Trust; The Ian Askew Charitable Trust; Baker Charitable Trust; Miss G Barfield; Mrs Sarah Bartlett; Mr Clifford Bell; Mrs B Calder; Carr-Gregory Trust; Mr Geoffrey Church; Mr Sidney Cole; Condon Family Trust; The Ruth & Charles Corman Charitable Trust; Mrs Felicity Crofts; The Drapers' Company; Dyers' Company Charitable Trust; Gilbert & Eileen Edgar Foundation; Mr Ken Edis; T F C Frost Charitable Trust; Dorothy Hay-Bolton Charitable Trust; Douglas Heath Eves Charitable Trust; Mr David Hook; Horizon Asset LLP; Lalonde Trust; Linden Trust; Marshall & Viggars Charitable Trust; Robert McAlpine Foundation; Miss Sheila Miller; Mrs Penelope Moody; Nationwide Building Society; Owls of Pill; Payne-Gallwey Charitable Trust; Pixiella Trust; Mrs Georgina Quincey; Ms Imelda Rice; Ms Margaret Riddington; Dr Susan Sanderson; Savills; Mrs Sheila Shepherd; St Stephens Ladies Group; Mrs Maureen Stacey; The Oliver Stanley Charitable Trust; Mr John Stevens; Betty Stott Charitable Settlement; Joseph Strong Frazer Trust; Mrs Janet Tatlow; The Tilehouse Trust; Mr John Timperlake; The Traynor Foundation; James Tudor Foundation; The Tula Trust; Mr Robert Washburn; Mrs Joyce Wetherell.

The National Eye Research Centre would like to thank all those who have made gifts over the past year, including those who prefer to remain anonymous. We are grateful for all your donations, large and small, but space prevents us from acknowledging you all here. Each and every one of you plays a vital role in advancing progress towards new treatments for eye diseases. Thank you.

Administrative information

Patrons	The Most Honourable The Marquess of Reading
Vice Presidents	Prof John Armitage OBE Prof David Easty MD FRCS Prof Andrew Lotery MD FRCOphth Prof John Marshall MBE Lady Wills
Ambassadors	Mr Julian Jackson Dr Amit Patel
Trustees	Mr Rodney Grey FRCS FRCOphth (Chair) Maj Gen (Retired) Chris Callow CB OBE FFPH Mr John Cottrell MA FCA Dr Dolores Conroy (appointed 23 April 2019) Mr Robert Drewett DL Mr Philip Jackson (appointed 1 October 2018) Mr Sidath Liyanage (appointed 1 October 2018) Mr Adam Ross MBChB, FRCOphth, FHEA, CertMedEd Mrs Christine Wall (resigned December 2018) Mrs Cathy Williams (appointed 1 October 2018)
Scientific Advisory Committee	Prof Sobha Sivaprasad DM FRCOphth FRCS (Chair) Miss Clare Bailey MD FRCP FRCOphth Prof Alastair Denniston MA MRCP FRCOphth PhD Prof Chris Inglehearn BSc PhD Dr J Arjuna Ratnayaka BSc MPhil PhD Prof Alan Stitt Prof Marcela Votruba PhD FRCOphth Dr Anthony Vugler Prof Andrew Webster FRCS FRCOphth
Director of Research	Prof Andrew Dick MD FRCS FRCP FRCOphth FMedSci FSB
Chief Executive Officer	Laura Serratrice

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Please consider supporting us in this way.

www.nercuk.org/gift-in-your-will

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