SIGHT RESEARCH UK

Every patient matters: turning science into sight

Annual Report 2019-20

Who we are

We are a community of supporters, researchers, patients, healthcare professionals, and fundraisers, working together towards our shared goal: to bring forward the day when sight loss and blindness are a thing of the past.

What we do

We fund research that is poised to provide new and more effective solutions for patients - be it in diagnosis, prevention or treatment.

Together, we can beat sight loss faster.

Great past, greater future

Sight Research UK started life as the National Eye Research Centre in 1986. It was founded thanks to the generosity of patients who wanted to support more research into eye conditions to find new and better treatments.

Thirty-five years on, we are still true to that original vision. You, our donors, trust us to spend your money to achieve the outcome you have told us you hope for the most – bringing forward an end to sight loss and blindness.

Spurred on by your wishes, and encouraged by the advances we have contributed to over the last three decades, we have launched a new research funding strategy that will get us even closer to making a tangible difference to patients – and faster, too.

On page 6, you can read about how the projects we will fund on your behalf in the future will help to make that crucially important leap from discoveries in the laboratory to potential new treatments in the clinic.

A new approach to research funding was not the only thing that you thought we should consider. After consulting with hundreds of donors and members of the public, we concluded that we needed a new name to better describe who we are and what we do: Sight Research UK. Always conscious that it is your money we are spending, we have re-branded for free.

A huge thank you to every single person who took part in our consultation in the summer and autumn of 2020. At a time so troubled for us all, when our immediate personal futures felt so uncertain, we dug as deep as we could and, together, we created a powerful vision of hope for those living with eye conditions – that new treatments could be found sooner.

Whether you are a supporter, a researcher, a patient or a clinician, what you will read in the next few pages is a vision shaped by you.

Whoever you are, we hope you can recognise yourself in it and be inspired to continue to support this work so that, together, we can bring forward the day when sight loss and blindness are a thing of the past.

Thank you.

SIGHT RESEARCH UK

How decades of research have transformed the lives of patients

Over the past 50 years, pioneering surgical techniques and new drugs have transformed the treatments for eye conditions such as glaucoma, age-related macular degeneration, diabetic retinopathy, and some rare congenital diseases.

Sight Research UK supporters should be proud to have played their part in this journey by helping to fund ground breaking research that has advanced the treatment of cataracts, corneal dystrophies, and uveitis, among others*.

Treatments like these are available in our clinics today only thanks to decades of research investment worldwide...

Advancements in cataract surgical techniques and improvements in intraocular lens replacement technology since the 1970s have made cataract surgery one of the most successful treatments in all of medicine.

In the late 1960s, surgical trabeculectomy provided a technique to lower intraocular pressure (IOP) in glaucoma patients. Since 1996, prostaglandin analogues (PGAs) have provided a pharmacological alternative to lowering IOP with daily drops.

* Research funded by Sight Research UK in the late 1980s led to increasing the storage time for donated corneas from 48 hours to up to four weeks, paving the way to elective, outpatient surgery for corneal transplants. Since then, more than 80,000 people have benefited in the UK alone, and transplant success rates are improving all the time.

* In the only randomised trial of its kind, a study part funded by Sight Research UK between 1993 and 1998, provided clear evidence of the benefits of the second eye cataract operation. These findings fed into a new NHS policy in 2000 which has since recommended second eye surgery as good practice.

The advent of anti-VGEF drugs in 2005 provided the first sight-saving treatment for patients with wet AMD. There is still no treatment for dry AMD.

In 2014, the injectable, slow-release implant Iluvein was licensed to treat diabetic macular oedema providing efficacy for up to 3 years from a single injection.

* Since 2018, anti-TNF drugs have become an additional line of treatment for uveitis patients who don't respond well to steroids.

In 2019, the first gene therapy operation for wet AMD patients was performed in Oxford to assess its sight preservation potential.

In 2020, the NHS approved the use of new gene therapy drug Luxturna for people affected by two rare inherited retinal diseases: Retinitis Pigmentosa and Leber's Congenital Amaurosis.

* The asterisk denotes advances to which Sight Research UK funding directly contributed over the years. The rest are examples of transformational progress achieved through contributions from other funders globally.

We are grateful to all our supporters who are helping to fund research to beat sight loss faster. Together, we can drive the next decade of discovery.

Our new research funding strategy: translating science into sight

Despite decades of research, there are still too many unanswered questions about the treatment, diagnosis, and prevention of sight-threatening eye conditions. The chronic under resourcing of the eye research sector means that progress towards more effective options is slower and narrower in scope than it needs to be.

When we asked our supporters, as well as patients, carers, and health professionals across the sector, they said that what they wish for the most is for research to find new and better treatments, as soon as possible.

To accelerate progress that can benefit patients faster, we have decided to change the way we will fund research in the future. We have shifted our research focus from understanding the basic science of eye disease (discovery science) to translating promising scientific findings into potential new treatments (translational research).

Translational research involves bridging the gap between basic laboratory research and clinical trials. The goal is to accelerate new options to detect, diagnose, treat, or even prevent disease. An example of translating science into health we can all relate to is the development of the COVID-19 vaccines.

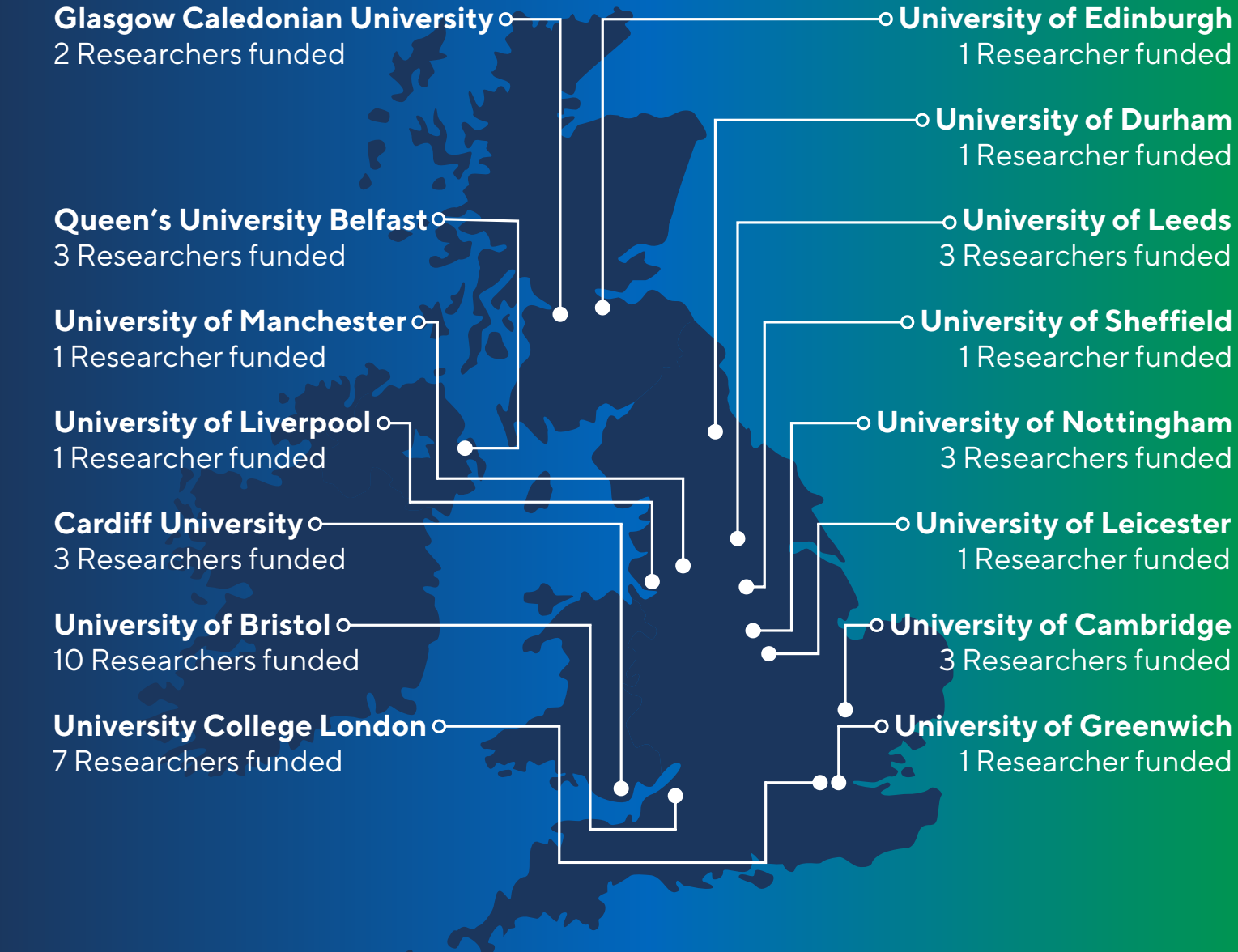
Across all fields of medicine there is a systemic lack of funding at the translational research stage which creates a block to science progressing towards being turned into the lifesaving and life-changing therapies for patients.
In the eye research sector, lack of funding is felt acutely at each stage of the research continuum, but translational funding in particular is in short supply.

Over the next five years, we will seek to fund projects that are poised to take the promising next steps towards initiating clinical trials. Our funding – your donations – will act as a catalyst to help researchers attract the significant follow-on grants from statutory medical research funders and the pharmaceutical industry.

Your support will help to unlock new hope for patients and their families.

Our current funded research

Our currently funded grants range from proof of concept projects, to PhD studentships and postdoctoral major research projects. All our grants are awarded through open competition. Applications are assessed in a two-stage process by an independent Research Advisory Board and are also peer-reviewed by relevant experts in the eye research sector, chosen among the international research community. At the end of our 2019-20 financial year (30 June), our active funding commitments totalled just under £1.3 million comprising 51 active grants held by 41 researchers across 17 UK research institutions. In 2019-20, we paid £614,355 towards existing grants.



Due to funding uncertainties during the first half of 2020, we postponed our annual April grant round, and through the rest of the year we awarded new grants for a total of £149,291. The Trustees established a Strategic Research Fund of £750,000 to ring-fence funds for future grants (from which five new grants were awarded in July 2020) and to meet requests for costed extensions from projects that had been severely disrupted by COVID-19 restrictions.

Current research

In 2019-20, we awarded five new research grants focusing on various eye conditions from uveitis to diabetic retinopathy, myopia, and inherited retinal conditions. Here are just a few examples and you can read more about these projects and other currently funded research on our website*.

Melt ElectroWriting: beating sight loss with revolutionary technology
Dr Lucy Bosworth, University of Liverpool

Regenerative medicine has enormous potential to treat a multitude of currently incurable conditions – including eye diseases. Technology that allows us to fabricate new tissues to replace those damaged by disease or injury has the power to transform the lives of people with sight loss.

Melt ElectroWriting (MEW) is a new technology, appropriate for regenerative medicine, that manufactures micron-sized 3D scaffolds, which can be used in tissue engineering to facilitate the growth of cells. To put this in context, a micron, or micrometre, is one millionth of a metre. A human red blood cell measures about 5 microns across.

Dr Bosworth is the first person to explore the potential of this technology for generating ocular biomaterials, which could be used to treat multiple eye diseases.

Loss of vision in Leber's hereditary optic neuropathy and dominant optic atrophy
Dr Michael Gilhooley, University College London

Leber's hereditary optic neuropathy (LHON) and dominant optic atrophy (DOA) are inherited diseases that cause damage to the retina, resulting in vision loss.

The retina is made up of layers containing different types of cells, including a type of cell called retinal ganglion cells. In both diseases, these cells die because their mitochondrial function is diminished. One particular type of retinal ganglion cell, however, known as the intrinsically photosensitive retinal ganglion cell (ipRGC for short), has been shown to be more resilient to poor mitochondrial function than others – surviving late into the course of both LHON and DOA when most others have been lost.

Dr Gilhooley theorises that there are a number of genes active in ipRGCs, which protect them from damage caused by poorly functioning mitochondria. To test this, he will isolate ipRGCs from laboratory samples that have LHON and DOA. Using a state-of-the-art genetic technique, he will then determine which genes are active in different types of cells within the optic

Current research

nerve, including ipRGCs. This will allow his team to identify a list of genes that may be responsible for protecting ipRGCs against cell death in these two diseases.

The genes identified will then be manipulated in nerve cells grown in the laboratory from skin cells donated by patients with LHON and DOA.

Understanding and controlling blood vessel leakage in diabetic retinopathy
Dr Andrew Benest, University of Nottingham

Diabetic retinopathy is the leading cause of blindness in the working age population of the UK. Some 750,000 people are believed to have "background diabetic retinopathy" which may eventually progress to total blindness.

The high blood sugar levels associated with diabetes cause blood vessels at the back of the eye to leak, become blocked, or grow haphazardly, causing inflammation. Inflammation stops the retina from being able to detect light and colour, which progressively leads to blindness.

What's more, inflamed and growing blood vessels do not work effectively. They fail to deliver enough oxygen to the rest of the eye, which drives further leakage and proliferation of blood vessels.

Currently, diabetic retinopathy can only be treated by regular injections into the eye. Many patients require monthly injections, and aside from being unpleasant and inconvenient, the treatment carries an accumulating risk of adverse side effects and can also become less effective over time.

The focus of this study is to gain greater understanding of the ways in which the eye blood vessels undergo such changes with a view of developing new and more effective therapies.

Is the absence of a protein responsible for severe myopia?
Dr Tina Storm, University College London

Myopia, or shortsightedness, is estimated to become a leading cause of permanent blindness worldwide by 2050. People who are severely shortsighted are at significantly higher risk of developing sight-threatening conditions such as retinal detachment and macular degeneration in later life which can lead to permanent sight loss.

Very little is known about what causes high myopia on a molecular level. Patients that do not have a particular protein called megalin, go on to develop a very severe form of high myopia suggesting that this protein is crucial for normal eye development.

This study aims to improve our understanding of what causes severe shortsightedness and has the potential to identify new ways to treat or stop it.

Your impact

Research impact is driven by you: thank you for helping us to beat sight loss faster.

Today, technological and scientific advancements in medical research are opening new possibilities for the treatment and prevention of disease as never before. The race to develop COVID-19 vaccines – and its astonishing results – shows us just what can be achieved when researchers are given the resources they need.

We cannot thank you enough for supporting eye research through Sight Research UK. Each of you has their own reason for giving, but we wanted to share some others with you, too, so here are just three good reasons to continue to support eye research:

Every 6 minutes, someone is given the devastating news that they are going blind. That's 250 new diagnoses every day. Unless new treatments are found, another 1.5 million are predicted to lose their sight by 2050. **Investment in research is the only way to bring about a different future.**

On pages 4 and 5 there are just a few examples of how advancements in research have created better outcomes for patients the world over. While decades of discovery have improved the lives of patients, research into eye disease remains critically underfunded. **With your help, we can do more and faster.**

Even though 20% of people will experience serious sight loss or blindness in their lifetime, eye research receives only 1.5% of national research funding. Eye disease costs the NHS some £3 billion a year in direct costs, and this figure is growing. **Research can point the way towards new prevention strategies, tackling the root cause of eye disease and saving valuable resource – and sight - in the long term.**

Thank you so much for being part of our community, and helping to beat sight loss faster with your gifts. Here are just two recent examples, you can find out more on our website*.

Potential for optic nerve regeneration offers hope for future glaucoma patients
Professor Keith Martin, University of Cambridge

A research team led by Professor Keith Martin has found a new way to restore functionality to a damaged optic nerve. While the study is still at the early stages of investigation, the initial findings offer hope to one day restore sight to those who have lost vision because of glaucoma or eye injury.

How did they do it? We know that visual information is sent to the brain through the optic nerve. Nerve cells in the back of the eye (the retina) extend fibres (called axons) through the optic nerve and send visual information along them. Axons in the optic nerve degenerate during diseases such as glaucoma, which, in severe cases, can lead to a permanent sight loss. That's because, once lost, the connections between the eye and brain can't be regenerated.

A decade ago, it became possible to artificially regrow optic nerve fibres in the laboratory. Since then, the team has found a way of activating the regeneration in the optic nerve using gene therapy to deliver an enzyme called PI3K delta into the eye. This allows the fibres in the optic nerve to regenerate after injury, as well as preventing the nerve cells in the eye from dying (which can happen in advanced glaucoma).

These results point to a potential gene therapy for optic nerve regeneration. Perhaps even more excitingly, new ways of activating regeneration have been found which could pave the way to new options. For instance, growing axions through the optic nerve could help a transplanted eye connect to the brain and restore sight.

Towards an eye drop treatment for diabetic retinopathy
Professor David Bates, University of Nottingham

Diabetes causes blood vessels at the back of the eye to leak, become blocked, or grow haphazardly, damaging the retina, eventually leading to sight loss and blindness. The only available treatment is by regular injections into the eye, monthly for most.

A Sight Research UK funded study led by Professor David Bates at the University of Nottingham has shown encouraging results towards a highly promising new treatment for diabetic retinopathy that could be delivered in the form of eye drops.
The study found that targeting a gene called SRPK1 with the drug SPHINX31 is a viable treatment for diabetic retinopathy. The drug prevents the gene from enabling the production of a protein (VGEF) responsible for the damage to and the abnormal growth of retinal blood vessels found in diabetic retinopathy.

The goal now is to establish drugs that work in the same way as SPHINX31, which can be administered as an eye drop rather than direct injections into the eye. A clinical trial is already under way.

Our finances

INCOME

DONATIONS	**£176,232**
LEGACIES	**£839,710**
INVESTMENTS	**£55,892**
GIFTS IN KIND	**£15,175**

EXPENDITURE

RESEARCH GRANTS	**£614,355**
FUNDRAISING COSTS	**£118,683**
CHARITY MANAGEMENT AND GOVERNANCE	**£94,868**

TOTAL INCOME	**£1,087,009**	**TOTAL EXPENDITURE**	**£827,906**

It costs us 16p to raise £1*

* Our 5-year aggregate is 17.4p:£1. Legacy gifts still account for a significant part of our income. The Trustees are committed to ensuring that the charity can operate on a more sustainable footing. As we look to diversify our income generation over the next few years, and following the devastating effect of COVID-19 on charities in 2020, we expect our cost to raise £1 to increase temporarily. We will always spend your money prudently and maximise our investment in research.

We allocated £988,000 to research*

*As well as spending £614,355 to meet existing grant awards, we also committed an additional £988,000 to research funding, including the establishment of a £750,000 Strategic Research Fund.

We employ 3 staff

Gifts in Wills

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. The largest contribution to this crucial investment was 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 1.5% 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 reach £3.5 million 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@sightresearchuk.org. **Thank you.**

Thank you to our donors

Sight Research UK would like to thank all those who have made gifts in our 2019-20 financial 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 to beat sight loss faster. **Thank you.**

We received donations in memory of:

Joan Blake
Margaret Bellwood
Thelma Bushell
Freda Brown
Elizabeth Corson
Robert Hopper
Norma Lorton
Tom Luckock
Kalwinder Singh Mangat
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We received legacies from:

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Thank you to our volunteers

Volunteers are the lifeblood of charities. You give generously of your time and expertise so that we have the support that we need to meet our objectives. You ask questions that keep us focused on the task at hand. You inspire us with the possibilities of what the future could look like for researchers and, most importantly, for patients. We thank you all for everything you do so that, together with our supporters, we can bring forward the day when sight loss and blindness are a thing of the past.

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Without gifts in Wills, 4 in 5 of our research projects would not happen.

Please consider supporting us in this way. For information on how to include Sight Research UK in your Will, visit www.sightresearchuk.org/legacies.

Thank you.

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