



national eye
RESEARCH CENTRE



Annual Review 2017-18

Who we are

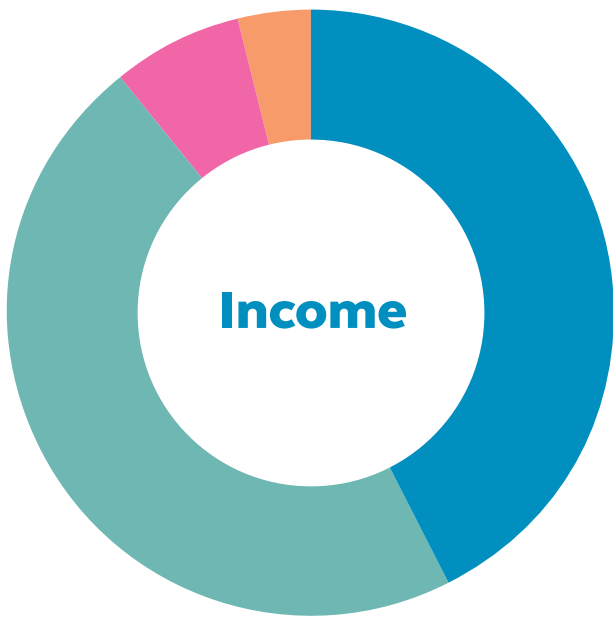
We help find new and better treatments for all eye diseases in both children and adults.

What we do

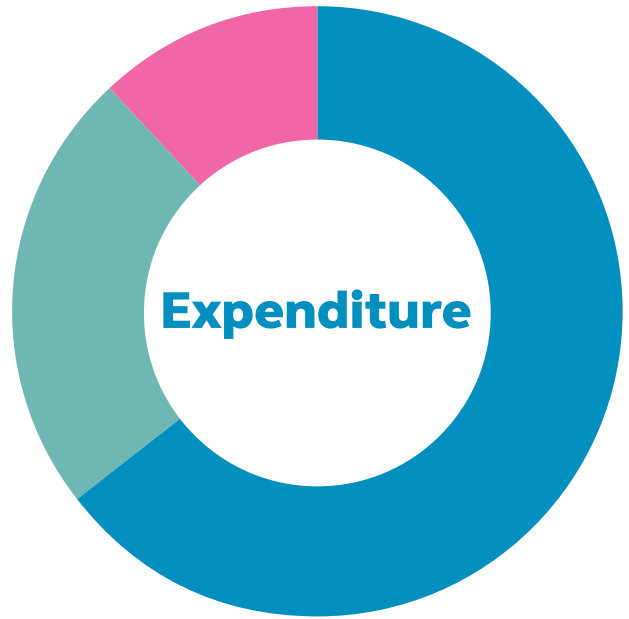
We fund eye research teams across the UK to find the causes of eye disease to develop new prevention methods and more effective treatments.

With your help, we can beat sight loss forever.

Our finances



- Donations: **£328,476**
- Legacies: **£361,840**
- Investments: **£54,520**
- Gifts in kind: **£28,985**



- Research grants: **£457,444**
- Fundraising: **£158,559**
- Charity management and Governance: **£79,343**



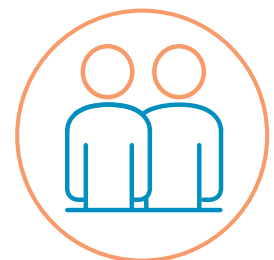
It costs us 28p to raise £1



We spend 70p of every £1 on funding research



Number of employees: 2





Chairman's statement

In 2018, I reached a personal landmark in my association with the National Eye Research Centre. For 30 years, I have been involved with the charity covering several roles which have culminated in the privilege of becoming its Chairman in 2013. As I look back on the last three decades, it is with an immense sense of gratitude to our donors and volunteers for their loyal support. Thanks to you, we have been able to invest over £17 million in research projects that are bringing scientists ever closer to answering some of the most fundamental questions about eye health and eye disease.

Secondly, I am extremely proud to have witnessed the evolution of the charity in becoming a truly national organisation, supporting the highest quality research all across the UK. Together with our charity partners in the eye research arena, we have established strong collaborations with some of the top research institutions, and we look forward to strengthening those partnerships in the future.

In October 2018, we were sorry to say farewell to our Chief Executive, Mike Daw, who led the charity for the last five years. Mike built solid governance foundations for the National Eye Research Centre which will enable the charity to grow in the years to come. Funding for eye research continues to be in very short supply compared with other medical fields. However, our commitment to helping find new ways of preventing and treating sight loss and blindness remains undiminished. I am delighted to welcome Laura Serratrice as our new Chief Executive; she brings both enthusiasm and expertise to lead the charity in the next phase of its development.

Rodney Grey
FRCS FRCOphth
Chair of Trustees

Our new Chief Executive



I am delighted to have joined the National Eye Research Centre and I am deeply grateful to all the donors who have supported our work over the last 30 years. I look forward to meeting as many of you as I can over the next few months because we have something very important in common. We share a deep belief in the fact that medical research finds cures.

We all know about the clinical advancements that research has brought to previously intractable conditions in so many areas of medicine. We are also keenly aware that eye research has been suffering from chronic underfunding. While much progress has been

made in the field, so much more needs to be done, but new advancements will only be made possible through increased funding in the sector.

I am hugely passionate about the transformative power of philanthropy when it comes to problem solving. I have seen it happen so many times and I am looking forward to working with my colleagues, other charities in the sector and, most importantly, with all of our supporters to help find more solutions to sight loss and blindness over the next few years.

Ms Laura Serratrice

Chief Executive



“We must do all we can to significantly increase funding for eye research.”

Research saves and changes lives and the UK government knows it

It has been proven time and time again. The rate of investment in medical research is in direct correlation to better outcomes for patients. Thanks to scientific discoveries, today, the number of UK deaths due to heart disease is a fifth of what it was 50 years ago. Childhood cancer survival rates have increased from 30% to 70% since the 1970s. Mortality and disfigurement rates for severe burns victims have fallen three to five-fold over the last 30 years, arguably thanks to the substantial advances in burn care that occurred in the 1980s. It does take a long time to take scientific ideas from the laboratory to the patient's bedside, but without time and money, there would be no positive transformation for patients and their families.

The UK medical research community was thrilled, therefore, to welcome the launch of the UK Dementia Research Institute in 2016, thanks to a £250m investment from the UK government and the two leading dementia research charities. An additional £40m boost from the UK government in 2018 is helping to further accelerate momentum in the fight against dementia which affects 850,000 people in the UK. That newly invigorated dementia research community is now set on an unprecedented path of discovery and innovation in prevention, diagnosis and treatment.

As a result, eye researchers are greatly encouraged by this bold level of investment from the UK government. A comparable commitment could benefit the 2 million people living with sight loss in the UK. Efforts to lobby government for additional investment in eye research have been under way for some time. Our likelihood of attracting transformative levels of government funding for eye research will be directly proportional to the quantity and quality of research results we are able to produce.

Our job as researchers, therefore, is to prove to the UK government that we are on the right track and that strategic levels of funding could enable an exponential growth in new prevention and treatment options. At current levels of funding (only 2% of all medical research in the UK is allocated to eye research), the number of people living with sight loss and blindness in the UK is set to double to 4 million by 2040.

We must do all we can to avoid this and our focus must be on generating a greater volume of high-quality research results through continuous investment in fundamental scientific research. It is now more important than ever that the National Eye Research Centre continues to provide funding for major research projects and early career fellowships. This will build capacity and secure succession within each area of eye research. Equally as important will be a focus on encouraging the creation of collaborative networks of experts across the UK that can tackle the grand challenges of sight loss.

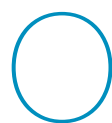
By working in partnership with other eye research charities, we can help to create an impetus that will be greater than any one organisation can achieve alone. With more philanthropic support in the sector, we can achieve more results. With more results, we can collectively make a stronger case to leverage the level of government funding that is needed to create a step change in eye research. Momentum has been slowly building in this direction but, with more funding, we are poised to accelerate it. Thank you so much for your continued support. As a donor, you are just as critical a part of the research team as the researchers themselves. I hope you will continue to join us in the quest to beat sight loss forever.

Professor Andrew Dick

MD FRCS FRCP FRCOphth FMedSci FSB

Director of Research

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 2018, our active funding commitments totalled **£1,643,058** comprising **34 active projects** across **16 UK research institutions**. In 2017-18, we awarded new grants for a total of **£433,000**.

University	Current Grants
Cardiff University	£180,688
Glasgow Caledonian University	£74,955
Newcastle University	£9,417
Queen's University Belfast	£61,166
University College London	£141,000
University of Bristol	£648,724
University of Cambridge	£59,183
University of Durham	£60,000
University of Leeds	£103,769
University of Leicester	£59,268
University of Liverpool	£60,000
University of Manchester	£60,000
University of Nottingham	£104,282
University of Oxford	£3,463
University of Sheffield	£10,000
University of Strathclyde	£7,143
Total	£1,643,058



Brain stimulation for Charles Bonnet Syndrome sufferers



Charles Bonnet Syndrome (CBS) is a condition that affects many people with sight loss and blindness and which causes them to experience often distressing and continuous visual hallucinations.

Researchers are still unclear about what causes Charles Bonnet Syndrome, but there is some initial consensus that the visual hallucinations might be linked to hyperactivity in a part of the brain known as the visual cortex. Through further research, we can learn more about the potential triggers in the brain, and hopefully find ways of switching them off.

Currently, the only available therapy for this condition is medication but these are not always effective and can cause some severe side effects. Researchers at Newcastle University are investigating brain stimulation as a potential, non-pharmaceutical treatment option. Transcranial direct current stimulation (TDCS) is a completely non-invasive method with significantly fewer side effects. Applied using small electrodes placed on the scalp, this stimulation can be used to target specific areas of the brain in order to modulate its activity, which may have an impact on visual hallucinations. This type of brain

stimulation has never been used with CBS patients, therefore much testing is needed.

Early results have been encouraging, with some patients reporting paler and smaller visual hallucinations, as well as some possible improvements to vision due to reduction in size of the hallucinations. Building on its early findings, the Newcastle research team is currently conducting a double-blind trial to assess the effectiveness of this type of brain stimulation. In the trial, two patient groups undergo brain stimulation or its placebo counterpart over a period of two weeks. In addition, the research is using brain imaging techniques to assess both changes in brain activity following stimulation, and differences between people with and without visual hallucinations in eye disease. We are delighted to help co-fund this research project with the Macular Society as it could make a huge difference to hundreds of thousands of people living with Charles Bonnet Syndrome.

**PhD Student Katrina da Silva Morgan
and Dr John Paul Taylor**
Newcastle University



Living with the nightmare that is Charles Bonnet Syndrome

Almost seven years ago, I got married. Only 12 months later, I lost my sight in the space of 36 hours due to a haemorrhage in both my eyes. Let me tell you, blindness is a lonely, tough and heart-breaking place, but with the wonderful support of my family and friends, I have rebuilt myself and I have a great life. Today, I am a husband and, just over two years ago, I became a father. I spend my day with my guide dog Kika, helping others who are living with sight loss and showing that disability – whatever form that may take – does not have to affect your goals in life. I raise awareness of the many frustrating barriers people with sight loss face but I also spread the word about the acts of kindness I witness most days. Because kindness is infectious, and we need more of it in the world.

There is something else I am passionate about: raising awareness of Charles Bonnet Syndrome (CBS). CBS causes people who are losing or have lost their sight to experience visual hallucinations. There is such little awareness of this dreadful condition that so many people with CBS never speak of the hallucinations they experience because they fear that they may be losing

their mind as well as their sight. Thankfully, that is not the case, but the hallucinations can be extremely distressing, and they never go away. We all seem to have our own personal types of hallucinations – some people see inoffensive things such as blobs of colour or geometrical patterns, for instance.

But many of us experience frightening visions of gargoyles in a crowd, strangers in our living room, or fires so real that we call the fire brigade. My personal hallucination is of a young woman covered in blood, mud, and tears. She stands in a terrifying silence and she follows me everywhere – on the train, on the tube, in the street. My wife has even heard me shouting at her in my sleep. My guide dog Kika can sense when I have a hallucination and she very sweetly puts her head on my knee to comfort me.

It helps, it really helps, but my hope is that research will soon find a way of removing this distraught, wounded young woman from my life.

Dr Amit Patel





Seeking solutions to retinal degeneration in inherited retinal diseases

The retina is the light-sensing layer at the back of the eye that converts light into chemical signals that pass to the brain to help us see. There exists a group of eye conditions that specifically affect the retina called inherited retinal diseases (IRD), which are caused by abnormal changes (also known as mutations) in our genetic code. IRDs are the most common cause of blindness in working age adults in England and Wales, and the second commonest in childhood. Currently, there is no cure or specific treatment available to patients.

Since IRDs have a clear genetic trigger, scientists could attempt to develop a gene therapy for each of the genes responsible. The problem with that approach is that there are currently approximately 250 genes that, if mutated, cause IRD, so developing a gene therapy for each would be extremely challenging, time-consuming and costly. However, there could be another way of preventing retinal degeneration which focuses on a single, fundamental aspect of retinal degeneration: the death of photoreceptors.

Photoreceptors form one of several layers of cells in the retina and they are the light-sensing cells. The cellular degeneration which leads to the death of photoreceptors is central to visual impairment arising from most diseases that affect the retina. Recent advances in the understanding of the mechanisms of photoreceptor death have emphasised a particular aspect that could hold the key to preventing these light-sensing cells from dying. Research findings have

shown that cellular death in photoreceptors is linked to a failure in energy production (metabolism), and in particular, a failure of sugar (glucose) being used by photoreceptors to produce energy.

Dr Mariya Moosajee is leading a research project with her team at University College London to seek to test the hypothesis that enhancing photoreceptor energy production can prevent or slow cell death, and therefore lead to the development of a universal treatment for IRDs regardless of their genetic basis.

The research team will assess the impact of several interventions on photoreceptor metabolism by monitoring the amount of energy molecules produced, oxygen usage, and patterns of gene function. Photoreceptor survival will be assessed by investigating the structure of the treated retina, measuring levels of cell death and testing the ensuing vision.

If the hypothesis is proved correct, Dr Moosajee's team will be able to further develop this concept through additional funding or partnership with industry in order to develop a gene therapy using the most efficient candidate to enhance glucose uptake or metabolism. This project has the potential to prevent, halt or slow retinal degeneration by enhancing energy production in a vast number of patients with incurable blinding disease.

Dr Mariya Moosajee
MBBS FRCOphth

University College London







Towards a new treatment for glaucoma

Glaucoma is the commonest cause of irreversible blindness. It is generally caused by high pressure within the eye which silently and permanently damages the nerve connecting the eye to the brain. It is growing in prevalence and an estimated 112 million people will be affected by 2040 across the world - most likely even more. Reducing the pressure in the eye has been shown across multiple clinical trials to prevent sight loss, but no current treatment provides an optimal solution. Treatments including drops, laser, and surgery are currently used to lower eye pressure, but all of these have limitations. Eye drops have to be used every day for life, yet they are often not effective enough. Pressure lowering laser is limited in its efficacy and can itself lead to visual loss. Surgery is associated with complications which can be sight threatening and also lead to blindness. Even if it works initially, surgery often fails over time due to scarring.

Dr Colin Chu and his team at the University of Bristol have successfully used a new method (called CRISPR-Cas9) to switch off a particular gene (Aquaporin 1) in order to lower pressure in the eye. This is done using a specially designed virus that reprograms a part of the eye anatomy called the ciliary body. The ciliary body serves a number of functions including the production of aqueous humour, which, in turn, is responsible for providing oxygen, nutrients, and metabolic waste removal to the lens and the cornea, which do not have their own blood supply.

The reprogramming triggered by the virus causes the ciliary body to reduce the amount of fluid pumped into the eye, thus reducing the eye pressure. Uniquely, the

treatment would be administered in a single injection and its effect should last for the rest of the person's life. Whilst an intravitreal injection sounds invasive, it is much safer than surgery and this type of injection is now so commonly used that it is routinely administered by nursing staff in outpatient clinics.

This study builds on findings from testing done on healthy eyes and it will now use the same techniques on an experimental model of glaucoma. The study will include specific assessments to ensure the treatment protects sufficiently against nerve damage. The research team will also finish testing tissue from eyes donated for human transplantation, to be confident that the approach will work in patients. In addition, it will target two other genes (Aquaporin 4 and Carbonic anhydrase 2), to see if the reduction in pressure can be further improved.

If successful, patients could be finally free from the disadvantages of daily drop administration, but also from risk-prone surgery and even lifelong hospital monitoring. The impact for the developing world might be even greater, by providing enduring treatment of glaucoma that could be safely administered by low skilled medical staff, making this a treatment option that could be made available on a vast scale.

Dr Colin Chu
FRCOphth

University of Bristol



Developing a model of corneal dystrophy to seek alternatives to invasive surgery

The cornea is the transparent tissue situated at the front of the eye. It protects the eye from the external environment and focuses light onto the retina. The innermost part of the cornea is made up of a specialised layer of cells called corneal endothelial cells. These cells perform a pump-like mechanism removing water from the outer layers of the cornea, which, if left to accumulate, causes corneal swelling and clouding leading to loss of vision and sometimes blindness.

When this accumulation of water happens, a disease called Fuchs endothelial corneal dystrophy (FECD) occurs. This condition is characterised by corneal endothelial cell death and it is a common, age-related disease estimated to affect more than 4% of people over the age of 40. Recent studies have shown that, in about two thirds of cases, FECD is caused by a genetic mutation, in other words a mistake, in the expression of a gene called TCF4.

Invasive corneal transplantation surgery is currently the only treatment option available to restore vision and prevent blindness for these patients. This treatment relies upon specialist facilities and is dependent on the availability of healthy donor material, of which there is currently a global shortage. Graft rejection and the need for systemic immunosuppression in some individuals, coupled with the global ageing population, highlight the need for alternative and effective treatment strategies to be developed for this condition.

Dr Alice Davidson's study at University College London aims to further understand the relationship between mutations in the TCF4 gene and FECD. In order to investigate the biological reasons for the disease, the project will use a model system that the research team has previously developed using donated corneal endothelial cells removed from FECD patients as part of their planned surgery. This model will be used to test the response of diseased cells to potential new therapies for FECD designed to target the common TCF4 mutation that causes disease.

The cell model of FECD will also be used to enhance our understanding of the biological reasons for disease. In particular, cutting-edge technology will be used to develop a genetic test for FECD that will have the potential to accurately identify pre-symptomatic individuals. This would provide a critical window of opportunity to prevent and treat the condition before sight loss occurs in the individuals whose TCF4 gene is susceptible to a mutation. Given the relatively late onset of FECD and the accessibility of the cornea, it is envisaged that discoveries made as part of the study will, in the longer-term, impact upon patient care by providing a pre-symptomatic diagnostic test and preventative therapies for FECD to reduce the need for corneal transplantation.

Dr Alice Davidson
University College London



The Big Blind Walk



We are hugely indebted to outstanding supporter Julian Jackson for completing his epic 8-week challenge, the Big Blind Walk, in May and June 2018. Walking from Land's End to John O'Groats, Julian has raised over £45,000 in support of eye research. Through the robust media coverage of his gruelling journey, however, he has raised so much more than money. Julian and his support team have increased awareness of the many and varied impacts of sight loss, of the importance to further develop our understanding of the science behind vision and eye disease, and the woeful lack of funding for this important area of medical research. Every pound raised is crucial.

Julian was joined by his wife Laura and daughter Imogen, as well as by several guides and friendly passers-by along the journey. From volunteers, to Buddhist monks, to members of the military and even royalty, he is extremely grateful to each and every one of them:

"I want to especially thank my guides who gave up their precious time and put their busy lives on hold to expertly navigate the route, steer me around obstacles and over

difficult terrain, constantly describe the environment around me and generally keep me going during many long days."

When it hits, sight loss impacts the whole family and everyone's life must change and adapt. For this reason, Julian reserves his biggest thank you to his wife and daughter for helping him complete his tenacious challenge. And along the way, he was touched by the warm welcome and the interest he received everywhere he went.

"The most exciting thing of all was that the many people I met during my walk appreciated the critical importance of nailing the causes of sight loss and not solely managing the symptoms or simply providing practical support, however understandably important that is."

Julian's energetic and adventurous support for the National Eye Research Centre does not end here. He and his team at VisionBridge are already busy planning an even greater challenge for 2020 to raise even more money for eye research. Details will follow subject to sponsorship.





A round of golf to support eye research

Long-standing supporter Ian Richmond helped to raise over £700 organising a Golf Day with eight teams taking part on a stunning autumn day at the Mendip Spring Golf and Country Club.

Our focus continues to be on helping to find the answers to some of the most difficult and most fundamental questions relating to the eye – how it works on a molecular and cellular level, what happens when eye disease occurs, and how sight loss may be prevented or even reverted. The work required to finding these answers relies not only on the outstanding expertise and ingenuity of world class research teams, but also on the funding needed to turn

ideas into clinical results. This is a very long process and never an easy one, which is why funding is so important to increase the volume of ideas being tested which will eventually lead to clinical applications changing people's lives for the better.

Thanks to the commitment of all our donors, the National Eye Research Centre can continue to invest in much needed eye research. Over the last 30 years, we have provided over £17 million to fund the work of world class research teams across the UK. We are very grateful to Ian for his wonderful support and that of all those who took part on the day.



A Gift in your Will

“The true meaning of life is to plant trees, under whose shade you do not expect to sit.

Nelson Henderson

We are immensely grateful to all the donors who have decided to support our work with a gift in their Will. Over the last 10 years alone, we have received gifts totalling over £3 million, ranging from £2,000 to over £300,000. Regardless of their size, each and every one of those legacies has helped enormously in progressing our knowledge of eye disease and in the quest for new treatment and prevention options.

We are truly humbled by the number of people who have decided to support us in this way, often without letting us know their intentions beforehand. An unexpected legacy is always a bittersweet surprise. On the one hand we are deeply grateful for the generosity, but on the other hand there is an undeniable sadness about not having been able to thank the donor while they were still alive and let them know what their gift might support one day. Sometimes, we are able to share our gratitude with a family member, but more often than not, even that is not possible.

Of course, a Will may be revised several times during a lifetime, and we fully appreciate that people's circumstances change over time. A gift that is pledged



in a particular version of one's Will, may well need to be removed at a later stage to make room for alternative arrangements for one's estate – a new grandchild perhaps, or a loved one who needs support, or indeed other charitable priorities.

However, if you have included the National Eye Research Centre in your Will, or are considering doing so, please do let us know so that we can thank you appropriately while we can! In addition, we would be delighted if you could help us by giving feedback on some of the new communications that we will be developing in the course of 2019. We will hold focus groups – both in person and remotely – with our donors and we would find it so helpful to hear as many points of view as possible. Please do get in touch.

Legacies, regardless of their size, make a tremendous difference to the amount of research we are able to fund and we are grateful for any gift received. Gifts in Wills are the most joyous gift that anyone can make. They are often the largest gift that anyone can afford to make, yet without parting with any money while they still need it – and anyone can change their mind

“Gifts in Wills, regardless of their size, make a tremendous difference to the amount of research we are able to fund.

at any time. But perhaps, most importantly of all, a gift in our Will is always inspired by something that has made a deep impression in us during our lives, and it is motivated by a profound and selfless desire to make something positive happen to benefit others after we are gone. Much like planting a tree that will provide shelter and beauty for those who come after us.



Thank you

In Memoriam

Mrs Thelma Beattie, Mrs Catherine Binnie, Mrs Yvonne Cottrell, Mrs D B Daw, Mrs Doreen Hagerty, Mrs Christine Hearn, Mrs Janet Hill, Mr Ronald James, Mr Walter Ladds, Mr John McParlan, Mr Paul Monk, Mrs Mary Nelson, Ms Rita Phillips, Ms Angela Porter, Mrs Enid Ramsay, Mrs Joan Staves, Mrs Esme Wilson.

Legacies

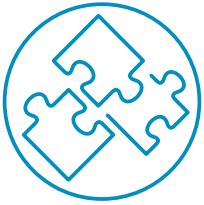
Mr Donald Derrick, Mr Joseph Goodworth, Major David Greenacre, Mrs Gabrielle McCafferty, Mr Peter Mann, Mr Robin Mills, Mr Arthur Potts, Mrs June Robinson, Mrs Pamela Tomkins, Mr Andrew Tullo, Mr Richard Wyld.

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The National Eye Research Centre would like to thank all those who have generously provided funding over the past year, including those who prefer to remain anonymous. We are grateful for all donations, large and small, but space prevents us from acknowledging them all here. Vital eye research would have been delayed or left undone without this generous support. **Thank you.**



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national eye
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