

Scientific Research Strategy

2024-2029

This strategy affirms that the charity will continue to support top-quality research, as judged by international peer review.”

Professor Alan Stitt

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# Foreword

I am delighted to endorse the Fight for Sight scientific research strategy.

The UK has always been at the vanguard of global vision research, and the charity will continue to play a critical role in supporting our research ecosystem. As a community of researchers, we seek to understand, diagnose, treat and prevent vision loss. These shared goals lie at the heart of this strategic plan.

As the Chair of the Research Grants Assessment Panel (RGAP), I am privileged to have a unique perspective on the breadth of cutting-edge science funded by Fight for Sight. This strategy affirms that the charity will continue to support top-quality research, as judged by international peer review.

Whether these projects are conducted in the laboratory, clinic or community, they will need to demonstrate scientific excellence and show potential to be translated into meaningful impact.

Indeed, it is now even more necessary for all researchers to involve active Patient and Public Involvement and Engagement (PPIE) at all stages of the research process.

Within this framework, the strategy highlights future plans to build greater research capacity by offering enhanced support for training the next generation of research leaders at all career stages. There are also plans to cultivate a multi- disciplinary, collaborative community of vision researchers who combine their expertise to deliver significant, real-world impact.

Likewise, Fight for Sight will develop new, dynamic partnerships with organisations that share its commitment to advancing vision research.

Prof. Alan Stitt

Chair, Research Grants Assessment Panel (2020-25)



ID: a strategy diagram. At the centre of the diagram is a man listening to his phone’s screen reader. The text surrounding him reads Patient Public Involvement and Engagement (PPIE). Surrounding the image are our four research principles:

Grant funding, capacity building, dissemination and impact, collaboration and partnership. Grant funding, a crucial pillar, is divided into four key themes, each highlighting its significant impact on our research activities: Understanding, Prevention, Diagnosis, and Treatment.

Our grant funding

Our funding helps researchers to increase understanding of eye diseases and conduct studies addressing vision loss at critical stages of the patient pathway:

The grants we fund over the next five years will focus on:

## Understanding

We will increase the understanding of how eye diseases and conditions start and develop.

## Prevention

We will develop new ways of preventing eye diseases and conditions.

## Diagnosis

We will enable eye diseases and conditions to be detected earlier.

## Treatment

We will develop new and improved treatments for eye diseases and conditions.



Case study: Retinitis pigmentosa

Prof. Majlinda Lako is advancing our understanding of the genetic cause of retinitis pigmentosa

Retinitis pigmentosa is an inherited retinal disease in which people lose peripheral and night vision.

Majlinda, who is a professor of Stem Cell Science, created models in the lab, enabling her to investigate the role of mutations in the PRPF31 gene, one of the most common causes of the condition.

She created the models using skin cells donated by people with PRPF31-mutated retinitis pigmentosa. From these skin cells, she created induced Pluripotent Stem Cells (iPSCs) with the characteristics of the condition.

## Retinal organoids

Using techniques perfected through a previous Fight for Sight grant, the team generated ‘retinal organoids’ from these iPSCs—clumps of cells that look and behave like a foetal retina. These ‘organoids’ contain photoreceptors and Retinal Pigment Epithelial (RPE) cells, the layer of cells which supports and nourishes the rest of the retina.

The team discovered that mutations in PRPF31 lead to faulty proteins accumulating in the RPE cells. This causes the cells to die, which in turn affects the photoreceptors, leading to progressive sight loss.

“You [could] stop the degradation, and at least patients ‘vision is not going to deteriorate further.”

Professor Majlinda Lako

Majlinda is now using the retinitis pigmentosa iPSCs to test gene therapy approaches that restore the production of functional PRPF31 protein. Her hope is that gene therapy at an early age could prevent damage to the retinal pigment epithelial cells and so prevent further sight loss.

“If you catch it early, then you [could] stop the degradation, and at least the patients’ vision is not going to deteriorate any further.”

Majlinda recognises the iPSC models would not exist without patients agreeing to donate their cells and feels a duty to make sure that research using the iPSCs really makes a difference for people: “For us, [they’ve] always been a resource created by the patients, for the patients.”

The iPSCs are now in the European Bank for Induced Pluripotent Stem Cells (EBiSC), which gives other researchers access to them to make their own discoveries.

Funding research

Supporting researchers with funding across stages in their careers is essential for building capacity and maintaining a thriving pipeline of vision researchers. We will fund:

## PhD Studentships

This is for supervisors proposing a PhD programme that aims to encourage the development of talented, highly motivated graduates in ophthalmic and vision research. We fund four-year Studentships aligned with the academic year that will lead to a PhD qualification.

Medical Research Council (MRC) / Fight for Sight Clinical Research Training Fellowships

The MRC runs a scheme for clinically active healthcare professionals to undertake a higher research degree (PhD, MD).

## Fight for Sight / RCOphth Zakarian Awards

For members of The Royal College of Ophthalmologists to gain experience and undertake ophthalmic and vision research, which could lead to further research opportunities. Those with no or limited prior research experience and/or those not in academic posts are particularly encouraged to help them get started in research.

## Small Grants

For applicants to collect preliminary/pilot data to make research ideas more competitive when developing larger, follow-on funding applications in vision research. Often in partnership with other funders, this helps to grow our reach and maximise our budgets.

## New Investigator Fellowship

The scheme will allow researchers who have completed their PhD to undertake a research project in vision research that could support them in the transition towards independence by establishing a research group. Our aim is to reintroduce the scheme in 2026/27.

The small grant award will lead to decades of output. It’s been the springboard to a whole new set of ideas and collaborations across the UK and overseas.”

Dr Siegfried Wagner Senior Research and Vitreoretinal TSC Fellow

## Project Grants

This call is for applicants proposing hypothesis-driven clinical or non-clinical stand-alone research projects that aim to address vision loss caused by any eye condition.

We fund three-year projects that aim to address an unmet need for those with or at risk of vision loss by investing in research that could ultimately lead to new ways to stop, slow down, or reverse it.

## Grand Challenges

Our aim is to fund a £2 million+ Grand Challenge Funding Call within the strategy period, leveraging funding from other organisations. This call will aim to answer the questions that have the most potential to impact people affected by vision loss and deliver transformative scientific breakthroughs.

We will promote interdisciplinary collaboration among scientists, clinicians, patients, and funders, accelerating research at pace. We will identify areas of unmet need through ongoing initiatives, such as the UK Clinical Research Strategy update of the James Lind Alliance research priorities.

Training and development

## Investing in people

While we fund specific research projects, we’re also investing in the skills and careers of those working to better understand, prevent, diagnose and treat vision loss.

We aim to train and retain the best researchers to work in this field.

We recognise that great researchers need diverse skills which stretch beyond the lab.

It could be skills that complement successful research, such as how to undertake meaningful Patient and Public Involvement and Engagement (PPIE), applying for grants or skills that enhance the presentation and dissemination of vision loss research.

We’re committed to funding these types of activities by working with partners and the research community.

## Bringing people together

We are also committed to bringing talented researchers together, so we’ll create an Alumni Network. It will enable early career researchers whose Fight for Sight funding has finished to stay connected to the charity.

We’ll share their news, help them apply for follow-on funding from other Fight for Sight schemes, and encourage them to act as Ambassadors for us.

The ways that we support better networking across our research network could include

* Facilitating networking through a mix of face-to-face and online events.
* Creating an online forum for our funded cohort. Introducing a mentoring scheme.

It is a huge help and support that we, as researchers and as clinician- scientists, know that there are charities like yours to support our patients and the groundbreaking research that we do.”

Dr Jasmina Kapetanovic, MRC Clinician Scientist and Consultant Ophthalmic Surgeon

## Measures of success

The research we fund should positively impact the lives of people with and at risk of vision loss. We will:

* Engage with experts with lived experience in our research activities.
* Have a thriving pipeline of sight-saving research and talent on the horizon.
* Build a large and growing community of collaborative, high-performing professionals steering and delivering Fight for Sight research (discovery, translational and clinical). Develop Alumni who become future leaders in vision loss research and active Fight for Sight brand ambassadors, creating new projects and partnerships for the future.
* Over the next five years, we will allocate £29m to grants for scientific research, social change, evidence-building, and impactful partnerships.

Sharing research evidence

## Sharing evidence

Dissemination and communication of research are integral parts of any research grant. Over the strategy period, we will build on activities to inform our supporters and the wider research community of our visionary research discoveries.

## Publishing research

We publish plain-language summaries of all funded research on our website and are keen to develop summary reports showcasing the outcomes of the work we fund. In addition, we’ll publish news stories and blog posts to share key research publications, developments and discoveries.

## Travel grants

Meeting colleagues and peers helps researchers build knowledge and grow networks at all stages of their careers. Through the ARVO Foundation, we’ll fund early-career researchers to attend the Association for Research in Vision and Ophthalmology (ARVO) annual conference.

## Conferences

Attending conferences allows researchers to disseminate their research findings, increase the profile of UK vision research and drive networking and collaboration opportunities. All our grant holders can use some of their funding to attend conferences such as ARVO (pictured).

Working together

Working together, we can maximise funding for vision loss research. We’ll also work with others to make the case for increased investment.

One of our core values is to work together within our organisation and in partnership. We’ve co-funded multiple research projects. For example, a Small Grant was co-funded with Alzheimer's Research UK in 2017. Thanks to that investment, the researchers created the AlzEye database, which has been used to show that changes to the retina in Parkinson's disease can appear up to seven years before other symptoms(1).

## Co-funded research

We’ll continue to co-fund research projects with other charities and organisations to maximise the funding available to better understand, prevent, diagnose, and treat vision loss.

## Understanding co-morbidities

Some conditions, such as diabetic retinopathy, also impact vision. We have co-funded projects across disease areas and will continue to do so.

## More investment in eye research

Research into vision loss is chronically underfunded. We will work with others within and beyond the sector to call for greater investment.

Case study: Amplifying young voices

Prof. Jugnoo Rahi is finding out more about young people’s experiences of vision loss

It’s vital we listen to the voices of young people on how best to treat and support them, which could benefit people such as Beth Cameron, pictured, who has vision loss.

In the UK, about 2 in 1000 children live with vision impairment. It’s vital we listen to their voices in considering how best to treat and support them. So, we funded Jugnoo Rahi, professor of Ophthalmic Epidemiology at University College London’s Institute of Child Health, and her team to find out more about young people’s experiences.

Jugnoo co-designed the Patient Reported Outcome Measures (PROMs) questionnaires with young people. This began with interviews with children as young as seven and up to 18 years of age. From these interviews, the team developed questionnaires that were then rigorously tested and refined with the help of a diverse cohort of around 200 children and young people.

The result was two PROMs questionnaires. The first was for Functional Vision, exploring how young people’s vision impairment affected their day-to-day activities. Another explored vision-related Quality of Life, that is, the difference between how a person would like their life to be and how they feel it is.

“Capturing [children and young people's] perspectives through these instruments provides a mechanism for them to influence decisions about their clinical care and inform assessments of the benefits of current or new treatments.” Prof. Jugnoo Rahi

For the first time, the questionnaires each had age-appropriate versions for children aged 8 to 12 and for young people aged 13 to 17.

The team licenced the questionnaires free of charge for academic researchers and professionals working with children. They are now being used in clinical trials for treatments for vision impairment and systemic conditions affecting sight. Some local authorities are also using them to evaluate rehabilitation services and education services.

As well as being well-known in the UK, the questionnaires are now being translated into several European languages. This will mean they can be used to compare the experiences of young people in different countries, as well as in multinational clinical trials.

The patient voice

We believe that people affected by eye conditions should have a voice in ensuring that the research we fund reflects the needs of people living with and at risk of vision loss.

Therefore, we will establish a Patient and Public Involvement and Engagement (PPIE) Panel during this strategy and incorporate it into our grant-making processes. We’ll also actively support researchers who want to connect to our panel.

We will offer opportunities to increase our understanding of the lived experience of vision loss and to co-design research projects and proposals, clinical trial protocols, and study information for participants.

We are committed to embedding good practice. As we evolve our approach to PPIE, we will ensure we meet all relevant UK Standards for Public Involvement and learn and embed good practices from other organisations.

## Equality, diversity and inclusion

People affected by eye conditions should have a voice in ensuring that the research we fund reflects the needs of people living with and at risk of vision loss.

We aim to create an inclusive culture with a diverse group of applicants, grant holders, early career researchers, involvement panel members, Grants Assessment Panels, and patient panel participants. We will:

* Foster a culture of inclusion and respect in all our activities, taking steps to include people from all relevant groups and communities.
* Collect and publish diversity data on our grant funding (applicants, grant holders and Grant Assessment Panels).
* Collaborate with and learn from larger funders regarding EDI strategies for research, playing an active role in efforts to improve practice across the sector.
* Work with the NIHR Clinical Research Network and Ophthalmology Specialty Group to support the implementation of their action plan for inclusive ophthalmology research. Promote inclusive research design that is reviewed in our assessment processes.
* Work with community groups to ensure we disseminate research findings and opportunities to traditionally underserved communities.

Acknowledgements

Fight for Sight would like to thank all those who contributed to the strategy's development by being interviewed, participating in online workshops, or providing feedback throughout the previous strategy period.

## Researchers interviewed

 Dr Gavin Arno: Principal Investigator/Honorary Senior Research Fellow, UCL and NIHR Great Ormond Street Biomedical Research Centre

Professor Maria Balda: Professor of Cell Biology, University College London Professor Mei Chen: Professor, Queen’s University Belfast

Professor Alastair Denniston: Consultant Ophthalmologist, University Hospitals Birmingham; Honorary Professor, Birmingham University

Professor Andrew Dick: Duke Elder Chair and Director of Institute of Ophthalmology, University College London; Director of the NIHR Moorfields Biomedical Research Centre

Dr Christiana Dinah: Director, Research and Development, Macula Service and Ophthalmology Research Lead, Ophthalmology Specialty Co-Lead North West London Clinical Research Network

Professor Lynda Erskine: Chair in Neurodevelopmental Biology at Aberdeen University Professor Jeremy Guggenheim: Professor in Myopia Research, Cardiff University

Professor Alison Hardcastle: Professor of Molecular Genetics, UCL

Professor Chris Inglehearn: Professor of Molecular Ophthalmology at University of Leeds

Professor Tim Jackson: Professor of Retinal Research, King's College London; Consultant Ophthalmic Surgeon

Dr Jasleen Jolly: Associate Professor, Anglia Ruskin University

Professor Majlinda Lako: Professor of Stem Cell Science, Newcastle University

Professor James Morgan: Professor in Ophthalmology, Cardiff University; Consultant Ophthalmologist

Professor Rachael Pearson: Professor of Developmental Neuroscience, King's College London

Professor Jugnoo Rahi: Professor of Ophthalmic Epidemiology, University College London

Professor Miguel Seabra: Honorary Professor, University College London; Nova Medical School, Portugal

## Researchers interviewed

Professor Jessica Teeling: Professor of Experimental Neuroimmunology at the University of Southampton

Professor Marcela Votruba: Professor, Cardiff University; Honorary Consultant in Ophthalmology

Professor Colin Willoughby: Professor of Ophthalmology at Ulster University

Professor Heping Xu: Professor of Ocular Immunology, Queen’s University Belfast All the attendees at two Fight for Sight Early Career Researcher Workshops held in January 2023.

## Past and present members of our research governance and advisory committees

Darren Barker: Trustee, Chair of the Social Impact and Scientific Research (SISR) Committee

Thomas Bjorn: Chair, Research Policy and Innovation Committee (RPIC) and former Fight for Sight Trustee

Professor Francesca Cordeiro: Trustee, Professor of Ophthalmology, Imperial College London; Consultant Ophthalmologist

Dr Heather Giles: Chair of trustees and former independent member of the Social Impact and Scientific Research (SISR) Committee

Dr Amit Patel: Trustee

Professor Roy Quinlan: Professor of Biomedical Sciences, Durham University and former Trustee

Paul Ryb: Independent Member of the Social Impact and Scientific Research (SISR) Committee

Professor Alan Stitt: Chair of the Fight for Sight Research Grants Assessment Panel; Professor and Dean of Innovation and Impact, Queen’s University Belfast,

 Louisa Vincent, former Co-Chair of Trustees: Trustee

## Case Studies

Conducted and written by Dr Richard Berks

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