

# Retina UK Manifesto

Working towards a brighter future for those with inherited sight loss.



## Introduction

Retina UK is the only UK charity dedicated solely to supporting people affected by inherited sight loss. Our driving focusses are to enable people with inherited sight loss to live well with their condition, and ensure that treatments are made available to those who want them.

For this to happen, Retina UK have identified four key areas that need to be addressed: Investment in Research and Development, Workforce Investment, Enhanced Data and an IRD specific registry and the production and the production and adoption of a Health and Social Care Pathway for Progressive Sight Loss

We will work with the government, regulators and other stakeholders to pave the way ensuring these four areas are achieved.



Join Retina UK in driving change and advocating for a brighter future for those with inherited sight loss.

Retina UK

Whiteleaf Business Centre

11 Little Balmer

Buckingham

MK18 1TF (UK)

General Tel: (+44) 01280

821334

Email: [info@RetinaUK.org.uk](mailto:info@RetinaUK.org.uk)

**RETINA**UK  
WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

## 1 Investment in Research and Development

- Collaborate with partner organizations to lobby the government for increased funding and support for R&D in inherited sight loss.
- Build an attractive regulatory framework to incentivize clinical trials and enable patient access to novel treatments.
- Invest in supply chains and infrastructure needed to deliver cell and gene therapies.



## 2 Workforce Investment

- Recruit and retain specialist therapies workforce to meet the anticipated growth for these treatments.
- Prioritise multidisciplinary training and education pathways for advanced therapies.
- Deliver commitments in the NHS Long Term Workforce Plan.

## 3 Enhanced Data Set and Registry

- Advance medical research through comprehensive patient registries.
- Accelerate drug development by providing data access to pharmaceutical companies.
- Improve patient care through monitoring treatment outcomes and identifying best practices.
- Enable precision medicine through biomarkers and genetic variations data.
- Contribute to economic growth by attracting investments and fostering innovation.



## 4 Health and Social Care Pathway for Progressive Sight Loss

- Develop a dedicated Inherited Retinal Dystrophy (IRD) Eye Care Support Pathway.
- Address pain points of progressive sight loss through clear information, practical and emotional support.
- Recognize evolving needs and provide a dynamic tool adapting to individual journeys.
- Mitigate economic and mental health implications through early intervention and increased access to treatment.