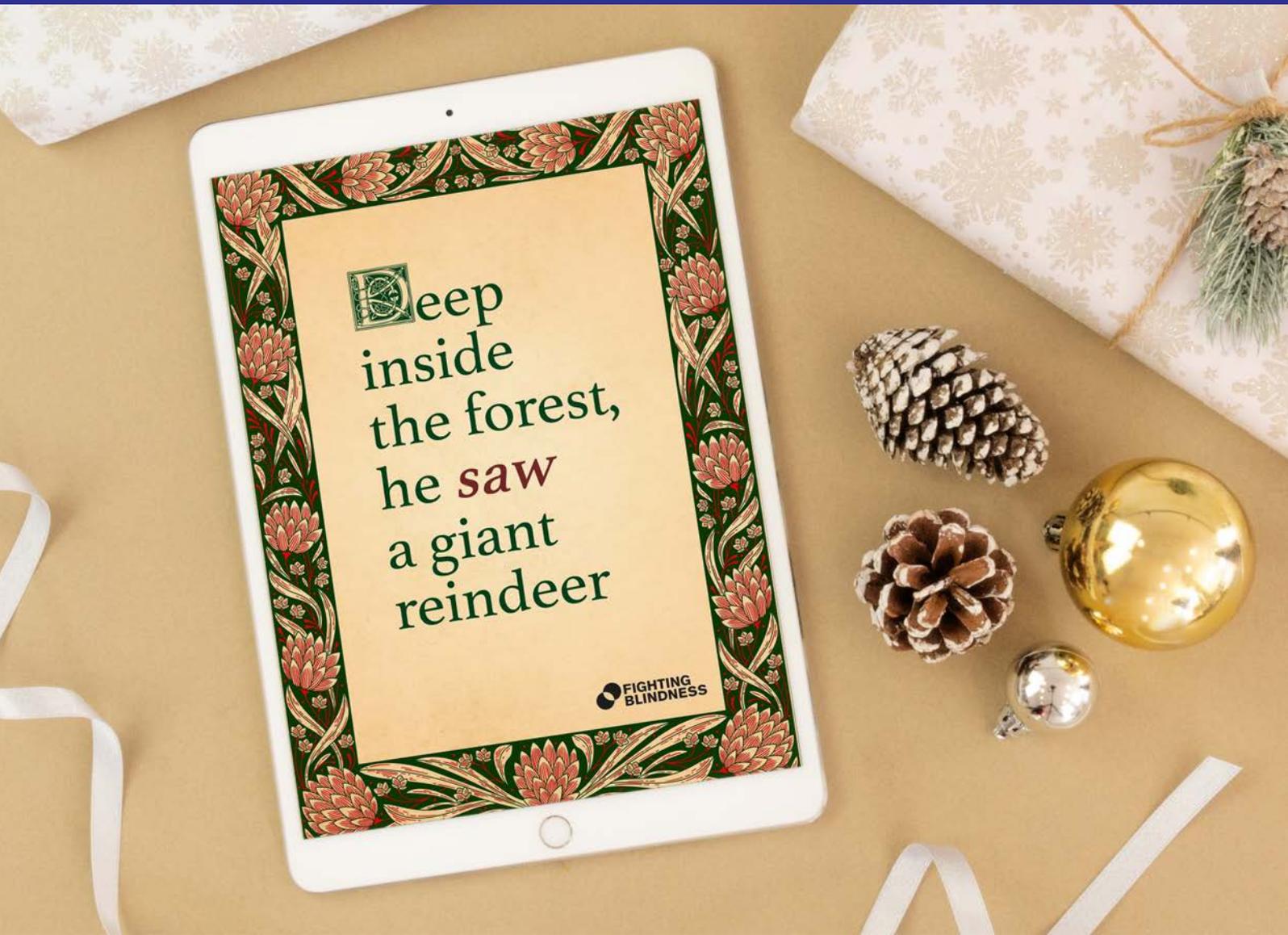


# Visionaries

Fighting Blindness Newsletter | Winter 2020



**In this issue...**

**Success at Retina 2020**

**Contact your local TD**

 **FIGHTING  
BLINDNESS**  
Cure. Support. Empower.

Dear members, supporters and friends,

I hope this newsletter finds you and yours healthy and safe. It has been a year like no other – one we will never forget. As a nation we can be proud of our response – community spirit is alive and well in this country.

As a small Irish charity, we are so grateful for your community spirit and generosity this year – it was a lifeline for our organisation in such a difficult year.

Despite the difficulties faced by the entire country this year, our team – like many members of our community – met the challenge with flexibility, resilience and determination. Our charity not only survived but – in terms of innovation – I'm happy to report that we rose to the challenge.

Our Support Service moved all their services online – and saw attendance increase by 400% in some cases. New peer support groups have formed and are at full capacity. This year – we supported more people than ever before.

Our two day conference, Retina, also moved to a virtual platform and attendee numbers quadrupled. We attracted delegates and speakers from all over the world – sharing groundbreaking research and knowledge on retinal disease.

Our researchers continued to work hard and just last month a team at Trinity College Dublin, led by Prof Jane Farrar, developed a gene therapy

that could potentially lead to a new treatment for an eye disease causing progressive loss of vision. Find out more on page 7.

2021 will bring an opportunity to realise the dream that our founding members had, a cure. Luxturna™ is a new gene therapy for the treatment of inherited retinal diseases.

To make this happen we need your help. On page 11 we outline how you can support our Luxturna™ campaign. There are three simple steps you can take that can make a big impact on the approval of the life-changing gene therapy in Ireland.

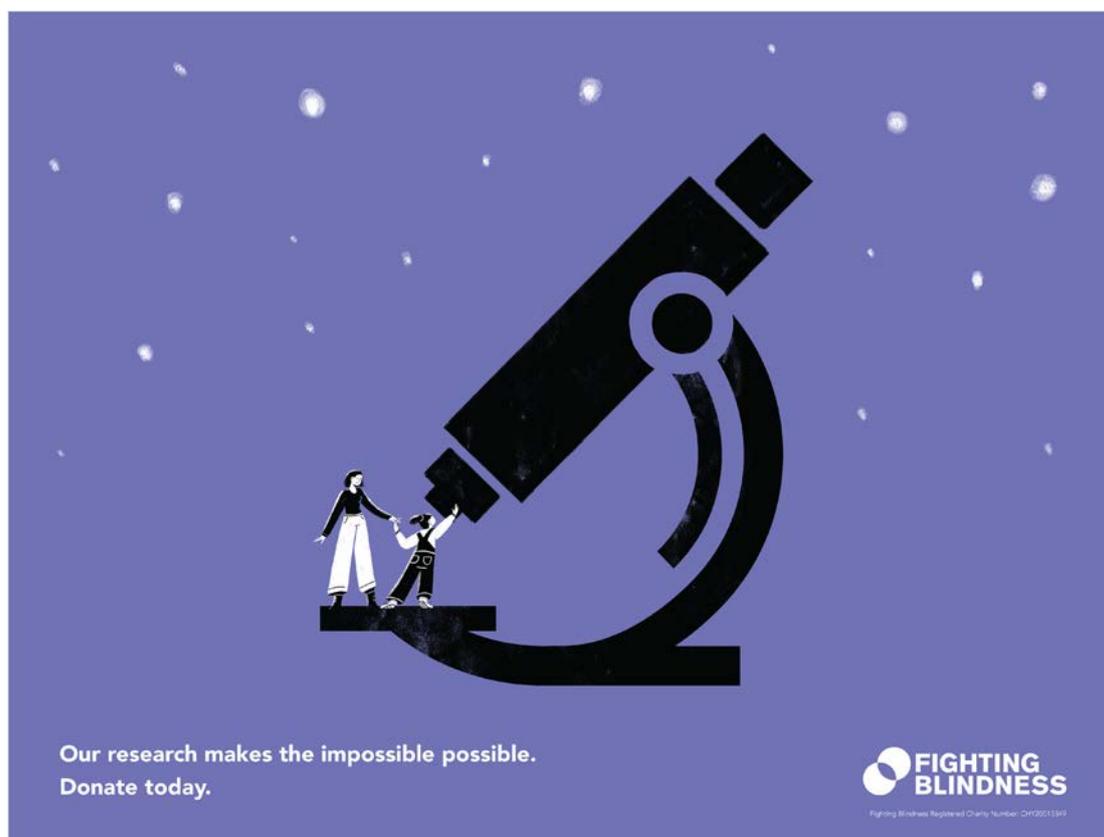
Finally, in the coming days we will be sending out our Christmas fundraising appeal, which also features on the front and back pages of this newsletter. The theme is 'fairytales' – because our scientists are helping to make fairytales a reality through the discovery of sight restoring therapies. If you can – please consider making a donation to enable us to continue our work in 2021.

Take care of yourself this Christmas, the end of the pandemic is within reach but continue to adhere to the recommended guidelines, we don't want to fall at the last hurdle.

I, and the entire team, wish you and yours a very happy and peaceful Christmas.

Kindest regards,  
Kevin Whelan  
CEO

## New advertising campaign for 2021



**We're proud to be a JCDecaux Charity of Choice for 2020 – 2021. The partnership – in place since 2018 – provides our charity with free nationwide outdoor advertising space. In late December and early January, our latest campaign will roll out across the country.**

Creative agency, In the company of Huskies (who donate their professional services), worked with us to create our latest advert 'Stargazing'.

The work features an illustration of a small girl, holding her mother's hand, whilst looking up a medical microscope to the stars.

The microscope symbolises a telescope. The tagline reads 'Our research makes the impossible possible. Donate today.'

The new work represents the outstanding achievements of our own funded researchers and of researchers around the world. Specifically – it represents the advancements made in gene therapy.

Gene therapy is a technique that modifies a person's genes to treat or cure disease. It's a revolutionary technique that is at the forefront of medicine and is restoring sight. Gene therapies – such as Luxturna™ – are restoring sight. The investment in research on a global level has made gene therapy possible.

We wanted to run a creative campaign that carries an optimistic and hopeful message informing the Irish public that investment in research is working. Research is saving sight.

## Virtual success for Retina 2020

**Like many other things this year – Retina 2020 was a very different experience.**

For the first time in 21 years of running the conference, and in line with Covid-19 public health guidelines, we transitioned the two day event onto a virtual platform.

A new and exciting challenge for our team, moving Retina to an online setting resulted in our highest number of attendees to date – 763 in total.

### Scientific Programme

On Friday 6 November, our [Scientific Programme](#) was officially opened by Deputy Neasa Hourigan, TD for Dublin Central, and Máire Geoghegan-Quinn, former European Commissioner for Research, Innovation and Science. Both spoke enthusiastically about the calibre of our speakers and of the research happening here in Ireland.

Hosted by Prof Breandán Kennedy (a researcher at University College Dublin) in a custom built virtual studio, highlights of the day included key-note speaker Dr Pearse Keane, an Irish consultant ophthalmologist at Moorfields Eye Hospital, who presented on his work developing artificial intelligence (AI) algorithms for the earlier detection and treatment of retinal disease.

The day's agenda showcased the significant work that is underway to truly understand the genetics behind retinal disease.

In the afternoon, through a series of sessions designed for early to mid-career researchers, we launched our new initiative Retina Network Ireland with support from Bayer Ireland and the Health Research Board.

Retina Network Ireland is a new all-island network for early to mid-career researchers, clinicians and allied healthcare professionals in the area of vision and retinal disease who are based in, or affiliated with, Irish Institutions.

The network will offer a number of free professional development opportunities to members – the first of which was delivered by award winning broadcaster Jonathan McCrea.

He delivered a talk from his Story Studio series about the words we use and how we use them in science communication. His talk explored the power of language and how we use it to educate, entertain and inspire.

Throughout the day four handpicked early investigators presented their outstanding research with the hope of securing the 2020 Geraldine Duggan Early Investigator Award. The competition was fierce and the winner was selected by our Fighting Blindness panel and an attendee poll.

Congratulations to Dr Ema Ozaki of Trinity College Dublin who secured the prize based on her Fighting Blindness-funded research into the treatment of retinal degenerative disease.



**Breandán Kennedy**

University College Dublin

Thank you to Novartis for presenting and sponsoring the award this year.

Our poster gallery also went virtual this year and close to 60 clinicians and researchers uploaded their work. The feature proved to be very popular and was supported throughout the day by a number of poster sizzlers – short audio clips from the researchers that succinctly explained their poster.

The final decision was very difficult but ultimately was based on the quality of the work and the level of interaction with the poster on the virtual gallery.

This year's Poster Sizzler Award went to Laura Whelan of Trinity College Dublin for her poster entitled 'Analysis of ABCA4 in over 1000 Stargardt disease probands identifies novel pathogenic deep intronic variants and reveals an enriched Irish variant'. You can [listen to Laura's](#)

[winning sizzler](#) on our YouTube channel. We are so proud to fund this outstanding research.

The quality was so high this year; we also wanted to highly commend the following posters:

- Zeinab van Gestel-Fadaie, Radboud University, the Netherlands
- Nuria Suarez Herrera, Radboud University, the Netherlands
- Ciara Shortall, Trinity College Dublin

Thank you to Bio-Sciences for sponsoring the Poster Sizzler Award 2020.

We'd like to extend a huge thank you to all of our speakers, attendees, members, ambassadors, official representatives, partners, sponsors and everyone who helps us to make Retina the outstanding international event that it is. It was a very different experience this year and we hope everyone enjoyed it.

# Launch of Retina Network Ireland

At Retina 2020 we launched our new initiative Retina Network Ireland, supported by Bayer Ireland and Health Research Board.

Retina Network Ireland is a new all-island network for early to mid-career researchers, clinicians and allied healthcare professionals in the area of vision and retinal disease who are based in, or affiliated with, Irish Institutions.

The goal of this initiative is to promote conversational debate, to provide professional development opportunities and to encourage greater cross-functional collaboration.

The network – which will be run by the charity through a closed LinkedIn group – will offer members free annual professional

development events and an opportunity to share research, news and knowledge.

Laura Brady, Head of Research, said, “Ireland punches above its weight when it comes to contributing towards the global effort to find treatments and cures for sight loss. It’s clear that Ireland presents a strong retinal research and clinical talent pool. We launched this network as we wish to support, nurture and promote the next generation of leaders in retinal research.”

To become a member of Retina Network Ireland, early to mid-career researchers, clinicians and allied healthcare professionals can request access through LinkedIn by searching ‘Retina Network Ireland’ in Groups.

## Don’t forget – Charles Bonnet Syndrome survey

Charles Bonnet Syndrome (CBS) is a side effect sometimes associated with sight loss. It can involve seeing visions or images that are not there.

For example, some people describe seeing animals sitting next to them or seeing people in Victorian clothing. Others may see objects, shapes or images of walls. Experiences can vary greatly from person to person.

Earlier this year, we launched a research study with Dr Alison Reynolds from University College Dublin to explore and understand the experiences of those living with CBS in Ireland.

A member of Alison’s team, Claire McSweeney gave a talk about the project at Retina 2020 and you can [watch it back online](#).

We’re asking everyone to please take the time to [fill out our online survey](#) – whether you experience CBS or not. It’s important to capture everyone’s experiences and we’re very grateful for your support.

In November, one of our members John Delany was interviewed on 'Today with Claire Byrne' on RTÉ Radio One about his experiences with CBS. We really recommend taking the time [to listen back online](#).

## Trinity researchers develop gene therapy for inherited vision loss disorder



**Exciting research, led by Dr Daniel Maloney and Prof Jane Farrar at the Trinity College Dublin School of Genetics, has resulted in [the development of a new gene therapy that could potentially benefit people with dominant optic atrophy \(DOA\)](#).**

DOA is an inherited condition and it usually causes moderate vision loss and colour vision defects. Severity varies and in some people it can result in complete blindness. There is currently no way to prevent or cure DOA.

A gene called OPA1 is important for providing instructions to ensure proper functioning of the mitochondria, the energy generator in the cells of our body. This gene is implicated or “mutated” in various mitochondrial diseases which are usually associated with ageing, but also includes DOA.

Like all research studies, a theory or approach must first be tested in cell and animal models before it can be trialed in humans. This study was no different and the first step was studying the approach in mice living with mitochondrial disease and also in genetically modified cells.

This type of gene therapy, as explained by Dr Maloney (pictured left) involves using “a clever lab technique that allows scientists to provide a specific gene to cells that need it using specially engineered non-harmful viruses.”

The OPA1-gene therapy successfully protected the vision function of mice living with dysfunctional mitochondria. Encouragingly, it was shown that this therapy also improved mitochondrial performance in human cells with OPA1 mutations. This boosts the mitochondria in producing more energy which helps protect from cell damage associated with disease.

An exciting take home message from this study is that this gene therapy may have a broader therapeutic potential and be applicable to other mitochondrial diseases including Alzheimer’s and Parkinson’s disease, and possibly other optic neuropathies.

Although there is a long research and development journey ahead before this approach could be considered as a treatment for patients, it is a promising step forward.

Congratulations to Dr Maloney, who was the recipient of Fighting Blindness’ Geraldine Duggan Early Investigator award at last year’s Retina conference, and Prof Farrar on this elegant study which was recently published in [“Frontiers in Neuroscience”](#).

## Fighting Blindness joins the Mental Health Reform



**Last month we were privileged to be accepted as a Governing Member of Mental Health Reform.**

Mental Health Reform is the leading national coalition on mental health in Ireland. They have over 70 member organisations, representing a broad range of interests like housing, disability, children's rights, human rights, ethnic minorities and many others.

Mental Health Reform provides a unified voice campaigning to drive progressive reform of mental health services and supports in Ireland. Governing members can participate in the Board structures of Mental Health Reform and have the right to vote at Annual General Meetings.

We are the first sight loss organisation to join the coalition and it marks an important step toward giving our community a greater platform on a national level.

Joining the organisation required a comprehensive submission and Peter O'Toole, our Head of Support and Counselling, liaised with Mental Health Reform's CEO throughout the process. We're delighted to join this influential network and will continue to work hard to represent the needs of our members and service users.

Visit the [Mental Health Reform website](#) to read more about their work.

## Virtual Living with Sight Loss courses

In June of this year we launched the Covid-19 friendly virtual version of our [Living with Sight Loss](#) course with a very enthusiastic response from participants.

Each course has been delivered using the Zoom™ platform. Over the course of five weeks we examine a number of subjects pertinent to people who suffer from sight loss.

We have had speakers from NCBI, Fighting Blindness, Vision Sports, Irish Guide Dogs and Sight & Sound Technology on each course to discuss the services they provide and answer people's questions as well as talking about the day-to-day challenges of living with sight loss.

Participants reported feeling empowered by the information and experience shared in the group.

Discussions were both practical and focused, while also being friendly and easy-going. A lot was gained from participants sharing their experience of sight loss. Everyone was on a different stage of their journey and the lessons shared were very useful.

People came away feeling they had more confidence about how to go about getting the supports they need and finding solutions to the problems that inevitably come with sight loss.

Participants found the online delivery very convenient, whilst also being interactive and dynamic. Using Zoom™ let us break out into smaller virtual rooms and we used this to further discuss the topics of the course. This got a definite thumbs-up from everyone!

## Visionaries Choir – the show must go online!



The Visionaries Choir have recommenced their weekly sessions on video conferencing platform Zoom™. They meet every Saturday and are always looking for new members.

Singing in a choir offers lots of physical and mental benefits, we encourage everyone to give it a go! If you would like to learn more, contact Frank on [fxjkelly@gmail.com](mailto:fxjkelly@gmail.com).

## Retina 2020 – Public Engagement Day success

**On Saturday 7 November we took to the accessible video conferencing platform Zoom™ to host Public Engagement Day 2020.**

Over 300 people registered to hear from international rugby player Ian McKinley, Judith Potts, founder of Esme's Umbrella Group, David Keegan, Clinical Ophthalmologist, Ben Shaberman, Senior Director of Scientific Outreach & Community Engagement at Foundation Fighting Blindness and Claudette Medefindt, Head of Science at Retina South Africa.

A strong theme that emerged from the day is the positive impact of moving our services onto a virtual platform in response to Covid-19 restrictions.

For many of our members and service users, this is a huge advantage as it allows them to stay connected and up to date without the stress that can come when travelling to a physical meeting. Many of you have told us that this feature is something you would like to see us retain into the future.

Our two day event closed on a high with the virtual presentation of our Paddy Byrne Empowerment Award. The award, presented by Dr Audrey Derveloy, Managing Director and Country President of headline sponsor Novartis Ireland, celebrates people who have made an impact on the lives of people living with sight loss.

This year, we are honouring Christina Fasser (pictured below) with a lifetime achievement award to mark her recent retirement and service as President of Retina International after 28 years. Everyone at Fighting Blindness would like to congratulate Christina and thank her for her hard work, dedication and energy.

Her acceptance speech was a fantastic and uplifting end to Retina 2020.

We'd like to extend a huge thank you to all of our speakers, attendees, members, ambassadors, official representatives, partners, sponsors and everyone who helps us to make Retina the outstanding international event that it is. It was a very different experience this year and we hope everyone enjoyed it.

The full recording of the Public Engagement Day is available to watch back on [our YouTube channel](#). We have also created shorter videos for each talk, also available on our YouTube channel.



## First gene therapy is still ‘under consideration’ – how you can help

In September, the National Centre for Pharmacoeconomics (NCPE) recommended that the life-changing gene therapy Luxturna™ not be reimbursed “unless cost effectiveness can be improved relative to existing treatments”.

Inherited retinal diseases such as retinitis pigmentosa (RP) and Lebers congenital amaurosis (LCA) are rare, serious and life limiting. These conditions cause progressive visual impairment, eventually leading to total sight loss.

Luxturna™ is the first and only medicine to address the underlying cause and positively impact on disease progression.

Early administration of this medicine leads to greater, life-enhancing benefits. It is already available in the UK and EU member states including Germany, France, Denmark and the Netherlands.

As such we, along with those living with degenerative retinal disease in Ireland, are very disappointed by this initial recommendation.

Luxturna™ is still ‘under consideration’ by the HSE Drugs Group and it is a critical stage in the decision-making process. During this period, we are seeking to mobilise all our efforts to ensure that we engage with local representatives.

We’re asking all our supporters to engage with

your local representatives to apply political pressure in support of reimbursement. Our community has funded retinal genetics research for nearly four decades.

**Here are three simple steps you can take to help:**

- 1. Visit our website to [download our Luxturna™ letter of support](#).**
- 2. Find out the contact details for your local TD by visiting [whoismytd.com](http://whoismytd.com).**
- 3. Print, sign and post our letter of support (ideally before Christmas week). If you prefer, you can [download our email of support](#) and email your TD. And if you like – you can do both!**

These three simple steps will go a long way to helping the decision makers listen, understand and deliver the right decision in the interest of our community and the futures of the people we serve.

Speaking to the media and raising national awareness will also be an important element of our campaigning in the coming weeks. If you are the parent of a child living with retinitis pigmentosa or Leber congenital amaurosis and you’re willing to share your story – please do get in touch with us.

If you have any questions or would like to speak to us about sharing your story, please email [research@fightingblindness.ie](mailto:research@fightingblindness.ie).



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