

Visionaries

Fighting Blindness Newsletter | Spring 2020



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

Welcome

Dear members, supporters and friends,

We are living in a very different Ireland since the last time I wrote to you. As Covid-19 spreads throughout the country, our everyday lives have changed unimaginably. It is an uncertain time, a worrying time. Unfortunately, for many, it is a lonely time.

I, and the whole Fighting Blindness team, wish you and your loved ones the best of health. Take care of yourself, take care of others.

Follow official guidance and encourage others to do so too. Together, we can – and will – defeat coronavirus.

Our team is adapting to the crisis. We are working remotely and, where we can, we are moving our services online. However, there is no denying it – this will be a very difficult period for our charity.

Our Chair, Prof Brendan Buckley, has written an open letter (page 3) outlining the impact on our organisation and how you – if you are in the position to – can help.

On page 4 we explain how our Support Services are changing and how we can help you.

We are using our social media channels to share accessible and important information about Covid-19. We're also sharing some great resources for looking after your mental health.

We have not stopped our vital work and will continue to support people living with sight loss.

However, what has stopped is our community fundraising. We rely on the generosity of the public for almost 90% of our income; this crisis will hit us hard.

If you can – please consider making a donation. You can [donate from the comfort of your own home](#) through our website using your debit or credit card. Small gifts from many people can make the biggest difference.

It is a difficult time. But, if history has taught us anything, we know that this too will pass. Human spirit will prevail.

Take care. Keep safe. Stay positive.

I'll be in touch again soon.

Kindest regards,

Kevin Whelan
CEO



A message from our Chairman

A chairde,

It is an unprecedented time for our nation. Throughout the uncertainty of the weeks ahead, we must remember what matters most – our health and our community.

Take the correct steps to look after your health and your family's health. If you can, help others in your community who are vulnerable. We need to work together as a country to defeat Covid-19.

I wanted to personally update you on what we, Fighting Blindness, are doing to adapt our organisation.

The laboratories that we help to fund are closed for the time being. But this does not mean that valuable research will be lost. Many of our scientists are working remotely and, when this is all over, the labs will reopen and work will recommence.

Our support services have moved from face to face to telephone counselling. Our peer support networks are going virtual. We're also sharing useful and accessible resources from official bodies across our social media channels.

Our team will continue to work hard but when it comes to community fundraising, there is only so much they can do from the kitchen table. Right now, we need support more than ever.

If you are in the position to do so, please consider [making a donation through our website](#). If you regularly engage with our services but are not a [member](#), please consider becoming one.

Every donation, small or big, will help us keep our doors open and continue to support people living with sight loss in Ireland.

Beannachtaí,

Professor Brendan Buckley
Chairman

fightingblindness.ie/donate

Covid-19 - how we can help you

Our support team is working hard and we intend to maintain our support for people living with sight loss, and their families, over the coming weeks. To find out more about our online services, email insight@fightingblindness.ie or call 01 674 6496. Our telephone line and email inbox are monitored during our working hours of 9am to 5pm, Monday to Friday.

Online ‘Living with Sight Loss’ course – for individuals, friends and family

Our popular Living with Sight Loss course is also available in an online format, it can be taken at your own pace, in the comfort of your own home. To sign up, visit our [Need to Talk web page](#).

Online ‘Emotional Support Vision Champions’ course

As an Emotional Support Vision Champion, you can help someone come to terms with sight loss. To find out more about this free, short online course, visit our [Need to Talk web page](#).

Counselling

Although we have ceased all face to face services, we have always offered confidential [telephone counselling](#) as an alternative option. Contact our team to find out more.

Check-in service

If you'd like the comfort of having a regular phone-call to help you stay connected but don't want to take part in counselling, we can arrange a time for one of our team to call you. They will check in on how you're coping and provide help to find appropriate resources.

Peer support groups

In addition to individual services, we offer [peer support groups](#) for people with a visual impairment to share their feelings and experiences with others facing the same challenges. These groups are now meeting online on a monthly basis.

Technology Exchange Club

The [Technology Exchange Club](#) is now meeting online. The Club is an informal gathering of people living with sight loss who wish to improve their daily lives through assistive technology. This support has become particularly relevant in recent times.

Mindfulness group

If you are interested in or are already practicing mindfulness in your daily routine you can join our [Mindfulness group](#) online every Wednesday from 11am to noon.

Success with Living with Sight Loss courses

In February, we ran our fourth Living with Sight Loss course in Letterkenny, Donegal.

The course is part of our [“Need to Talk” project](#) which offers counselling and confidence building courses in the border counties (Donegal, Louth, Sligo, Cavan, Leitrim and Monaghan). The course was fully booked and feedback has been overwhelmingly positive.

Living with Sight Loss helps individuals adapt to life with sight loss. It explores a range of topics including mobility and daily living, emotional wellbeing, eye health and peer support.

The course combines facilitated sessions and relaxed talks. It focuses on the different sources of help and support that are available and how to get them.

We will be running more courses in the border area throughout 2020. The dates are dependant on Covid-19 measures.

For further information, and to register interest in counselling or taking part in one of our confidence building courses, contact us on:

Phone: 01 674 6496

Email: needtotalk@fightingblindness.ie



Our Living with Sight Loss course is now online

Our popular **Living with Sight Loss course is also available in an online format.** It's available to everyone, regardless of location, and can be taken at your own pace, in the comfort of your own home.

The online version will explore the same range of topics as the face to face Living with Sight Loss courses. This includes mobility and daily living, emotional wellbeing, eye health, peer support and assistive technology.

Close family or friends have also found this course beneficial in understanding how they can support their loved one.

Many individuals who work with those with sight loss have taken this course and found it to be an invaluable learning resource.

To sign up, visit the [Need to Talk](#) section on our website.

Calling all Emotional Support Vision Champions

As an Emotional Support Vision Champion, you can help someone come to terms with the impact of sight loss.

Emotional Support Vision Champions are able to empathise with a person experiencing sight loss and have an understanding of their emotions.

They also have knowledge of the services available to people affected by sight loss, and can provide support and information.



The Emotional Support Vision Champions course is for people working with or supporting those affected by sight loss including:

- Ophthalmologists and optometrists
- Eye Clinic Liaison Officers
- Health and social care staff
- Mental Health Professionals
- Allied health staff
- Primary health care staff
- Volunteers
- Educational staff
- Community and voluntary service providers
- Public service providers

This free, short online course is designed to be completed in 80 minutes and certification is provided.

Further information is available on the [Need to Talk](#) section of our website.

Trialling a peer support group for partners

Late last year, we commenced a 12 week pilot peer support group for partners of those living with sight loss. Feedback was positive and participants recorded their emotional progress to measure success.

We were delighted to see a significant overall improvement in wellbeing and we hope to develop this service further in 2020.

We'll provide more details when we are ready to launch. We'd like to thank all the participants and our amazing group facilitator Emer.

“Very supportive group. Experiences are both very different and similar. Good to meet others in similarly challenging situations.”

“We have been waiting a long time for a service like this and are delighted it came along when it did.”

Counselling for Sight Loss training courses

In collaboration with RNIB and Vision UK, we held our first “Counselling for Sight Loss” training in Dublin last November.

It was followed by another course in Belfast in February, where counsellors from all over the country travelled to participate.

Due to the ongoing demand for the course, we will be running a second Dublin based training later in the year.

We are committed to increasing the number and abilities of counsellors in Ireland who are specifically trained to work with clients with sight loss.



Funding more ground-breaking research



A primary mission of Fighting Blindness is to fund vision research that has the potential to improve diagnosis or lead to the development of treatments and cures for those affected by sight loss.

Through the generous support of the public and our membership, we are currently funding fourteen exciting projects in universities and hospitals across Ireland, the Netherlands and United States.

These funded researchers are trying to find new genes responsible for inherited retinal degenerations, to protect and slow progression of retinal disease but also to improve our understanding of the biological mechanisms behind sight loss.

We are still committed, despite challenges around Covid-19, to follow through on our mission and support high quality research.

We're extremely fortunate to have excellent vision researchers and dedicated ophthalmology teams in Ireland.

We recently invited them and their international colleagues to submit new research ideas and proposals to Fighting Blindness under the [Health Research Charities Ireland \(HRCI\)](#) and the [Health Research Board \(HRB\) Joint Funding Scheme](#).

These applications will be rigorously reviewed based on scientific quality, [public and patient involvement \(PPI\)](#) and potential impact and benefit to sight loss community. We anticipate the review process to be completed towards the end of the summer and we look forward to announcing new research studies later this year.

You can visit the [Research section on our website](#) to learn more about these different research endeavours.

Target 5000 findings published in scientific journal

Target 5000 is a key priority and investment for our charity and its members.

It started life as a research study, expanding in recent years into a larger programme delivering clinical and genetic services to everyone in Ireland living with an inherited retinal degeneration (IRD). In January, key research outcomes were published in a scientific journal.

The paper, entitled [‘Findings from a Genotyping Study of Over 1000 People with Inherited Retinal Disorders in Ireland’](#), is the result of the generous participation of people living with an IRD and many years of hard work by the research team at Trinity College Dublin.

Analysing over 1000 DNA samples, [Target 5000](#) research has shed light on the genetic landscape in Ireland and identified the disease-causing gene in nearly 70% of study participants.

These research grade results are now undergoing clinical validation.

When available, important genetic information will be provided to participants and their families through our genetic counselling service.

For the remaining 30%, where the disease-causing gene has yet to be discovered, research groups in Trinity College Dublin and across the world are actively trying to resolve these cases.

The Target 5000 study highlights the high standard of researchers in Ireland and their significant contribution, at a global level, to understanding inherited retinal degenerations.

[A breakdown of the key findings from this research is available on our website.](#)



Counting the cost of living with sight loss

IRD COUNTS is a consortium of patient organisations (including Fighting Blindness) and industry partners working to establish the impact of inherited retinal dystrophies (IRDs) within the UK and Republic of Ireland.

Late last year the consortium released results from a cost-of-illness study (performed by Deloitte Economic Access) which examined, for the first time, the individual burden and economic impact of inherited retinal degenerations (IRDs) in Ireland.

This study reinforces the importance of Target 5000 and the critical role Fighting Blindness is playing in terms of investing in retinal research and facilitating the establishment of a national registry.

One of the key and stark findings of the study was the impact on well-being on those living with an IRD and parents of children living with an IRD. In fact, well-being accounted for over a third of the total costs associated with IRDs.

However, these costs are not taken into consideration in the evaluation of new medicines in Ireland.

We now wish to work with the Irish Government and other organisations to start a discussion about the patient experience and use this important data and relevant outcome measures to support and justify investment into expensive treatments.

We hope, with your support, that we can ensure access to exciting new therapies for Irish people.

We were delighted that the outcomes of this research were published recently in the [Clinical Ophthalmology journal](#), demonstrating its impact and contribution towards the wider community.

We'd like to thank all participants of this study. Without your feedback, we wouldn't have been able to produce such high quality and useful data.



Political advocacy - Manifesto 2020

When the general election was announced in early January we prepared a [Manifesto](#) with four key demands.

We emailed it to members, friends and supporters and asked them to raise the issues with their local candidates.

We approached national candidates and several representatives of the new Dail have agreed to meet us to see what can be done. Meetings with the new government and opposition will be arranged as soon as we can.

As many of you heard, we organised a march to Dáil Eireann for Wednesday, March 11, 2020. Support from members and supporters was fantastic and about 40 to 50 people signed up to take part.

However, due to growing concerns about the coronavirus, we decided to postpone the event.

We want to assure everyone that this is not the end of our political activities. We will keep you all updated on our plans by email and through our website and social media.

Fighting Blindness Manifesto 2020 Charter of Demands

Demand 1: Offset wellbeing costs

Reduce the cost of living with a disability. Provide access to resources such as medical cards, counselling services and personal assistance.

Demand 2: Cut waiting lists

Cut waiting lists for eye care through improved regional centres and staffing levels.

Demand 3: Genetic testing

Everyone has a right to a genetic diagnosis. A national registry will provide access to personalised medicine and clinical trials.

Demand 4: Access to therapies

Life-changing treatments and therapies are available. If the cure is waiting, we shouldn't be.

Event: From bench to boardroom, and beyond



To celebrate International Women's Day 2020, we hosted a breakfast event on Friday, 6 March, celebrating trailblazing women working across research and innovation.

Our theme, 'From bench to boardroom, and beyond', explored the different career paths our speakers have embarked upon and their on-going efforts to promote and facilitate research and innovation in Ireland.

Our fantastic panel featured:

- Dr Abigail Ruth Freeman, Director of Science for Society, Science Foundation Ireland
- Dr Audrey Derveloy, Managing Director and Country President, Novartis Ireland
- Eibhlin Mulroe, CEO, Cancer Trials Ireland
- Professor Jane Ohlmeyer, Chair, Irish Research Council
- Dr Victoria Brownlee, Programme Manager (Ireland), Athena SWAN

The event was chaired by Priscilla Lynch, Clinical Editor at the Medical Independent.

The panel discussed their careers to date, obstacles they have faced and advice they would give to young female researchers.

A [full review of the event](#) can be found in the News section of our website.

Before closing the event we announced the winner of our new Young Female Researcher Bursary – a €1000 career development award for a promising female researcher working in the area of sight loss in Ireland. The Bursary is proudly supported by its4women.ie.

To launch the Bursary, we asked researchers to summarise their research in the format of a tabloid headline. The winner was Rebecca Ward, a PhD researcher in UCD with her entry – "Plenty more fish in the SEE...and UCD researchers are using them to REEL IN a cure for childhood blindness!"

We would like to extend a warm thank you to all of our panellists, our chair, attendees, AIB Ireland for hosting and its4women.ie for their support.

Dates for your diary

It is our hope and expectation that our events will go ahead as planned later this year. We will continue to follow Government advice on Covid-19 (coronavirus) and will keep you updated on any changes. We will also keep you updated about Retina 2020 in the coming months. Your help is so important, now more than ever. To support our charity, you can [donate on our website](#).

Vhi Women's Mini Marathon

The 2020 Vhi Women's Mini Marathon, scheduled to take place on Sunday, May 31, will be postponed. This decision has been taken in light of the growing threat presented by Covid-19. The event will be re-scheduled to autumn.

To register your interest in taking part and raising money for Fighting Blindness please email fundraising@fightingblindness.ie with your name and contact details. Perhaps now is the time to dust off the running shoes and get ready for autumn!

Vision Walk 2020

Vision Walk is a four day walking festival taking place from Thursday 8 October until Sunday 11 October in Marbella, Spain.

We'll be joining 4000 other walkers and sun seekers as part of the Marbella 4 Days Walking Festival. We want you to take part and raise vital funds for finding a cure for blindness.

If you are interested in signing up to Vision Walk 2020 please email fundraising@fightingblindness.ie.

Glendalough Trail 2020

Join us for the Glendalough Trail 2020 on Saturday, 14 November – a unique running experience in a beautiful part of the country. We have a long course (15.5 km) trail run and a short course (8.6km) jog / walk option.

Booking will open in early 2020, please keep an eye on our website and social media channels. For more info visit www.glendaloughtrail.com or email fundraising@fightingblindness.ie.