Visionaries

Fighting Blindness Newsletter | Summer 2021

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FIGHTING BLINDNESS
Cure. Support. Empower.

Welcome

Dear members, supporters and friends,

Welcome to the summer edition of our Visionaries newsletter, I hope it finds you and yours healthy and well.

We had a busy start to the year and I'm very proud to announce we are certified as compliant with the Triple Lock Governance Award with Charities Institute Ireland.

Triple Lock status is awarded to charities that uphold the highest standards in transparent reporting, ethical fundraising and strong governance structures. This recognition is the gold standard for Irish charities to offer assurances to donors, members and the general public.

Continuing the good news, I'm very pleased to also let you know that our Retina 2020 conference was shortlisted for a CovidComms Award in the category of 'Best Online External Event'.

It bears testament to the quality and volume of work that our team pours into the conference each year. Speaking of, I hope you'll all join us for Retina 2021 on Friday 5 and Saturday 6 November 2021 – more details to follow shortly.

As promised in our spring edition, I'm delighted to introduce you to our new Research Manager, Dr Rachel Bermingham. Rachel joined us in April from the Irish Cancer Society. You can read more about her background on page 7.

Top Irish Paralympian Greta Streimikyte is kindly supporting the launch of Steps for Sight 2021. We're thrilled to have her on board and we're very hopeful she'll bring a medal home later this summer!

Our virtual challenge is proudly supported by its4women again this year and I ask everyone in Ireland to step up for sight this July and support our work.

Last month our team was greatly saddened to hear of the passing of our member and dear friend John Leonard.

John, who was living with age-related macular degeneration (AMD), was a dedicated member and passionate advocate for sight loss.

I would like to extend our sincere condolences to the Leonard family. May he rest in peace.

Kindest regards,
Kevin Whelan
CEO

Top Irish Paralympian steps up for sight this July

Runner Greta Streimikyte supports the launch of our fundraising challenge Steps for Sight.

Paralympic medal hopeful Greta, who is an ambassador for Fighting Blindness, is calling on people of all ages and abilities to walk, wheel or run to support the quarter of a million people living with sight loss in Ireland.

The Lithuanian-born 1500m runner's eyesight was damaged at birth. Born prematurely, Greta was placed in an incubator which led to retinopathy (damage to the retina). The 25 year old hasn't let her eyesight hold her back and Greta hopes to represent Ireland in the Tokyo Paralympic Games later this summer.

Steps for Sight aims to raise vital funds for our work. Participants are asked to walk, wheel or run a marathon (42km/26 miles) in the month of July or take part in our 10km Race Day on Saturday 31 July.

Fighting Blindness is one of its4women's charities of choice and the Irish insurance brand is sponsoring Steps for Sight for the second year in a row.

Greta is proud to be an ambassador for the charity, "It has been a difficult year for Irish charities and I'm delighted to use my platform to support Fighting Blindness. Steps for Sight is their main fundraising event this year – every cent raised will support their mission to cure blindness and support people living with sight loss."

Sign up for Steps for Sight today!

Retina 2020 shortlisted for a CovidComms award

We're delighted to announce that our Retina 2020 conference was shortlisted for a CovidComms Award in the category of 'Best Online External Event'.

The category recognises organisations that have been creative in their efforts to communicate with external stakeholders.

The judges were looking for events that were initially planned as physical ones and forced to adapt, or bespoke online events created to reach different stakeholder groups.

Retina is our annual conference; it brings together top international and Irish researchers and clinicians in the global effort to find treatments and cures for conditions causing vision impairment and blindness.

In response to Covid-19, we developed a virtual experience for Retina 2020 with Agency X, a strategic marketing agency specialising in creative healthcare communications.

The virtual meeting took place on Friday 6 and Saturday 7 November with a stream of live and pre-recorded adapted presentations.

We were shortlisted alongside the BT Young Scientist & Technology Exhibition and International Foundation for Integrated Care. The impressive wider nominee list featured Lidl, Three Ireland, Guinness and Boots Ireland.

Unfortunately we lost out to the BT Young Scientist and Technology Exhibition at the virtual awards ceremony on Thursday 27 May.

However, we are still delighted to have been shortlisted alongside national household names.

It bears testament to the quality and volume of work that our team pours into the Retina conference each year.

We hope you'll all join us for Retina 2021 on Friday 5 and Saturday 6 November 2021 – more details to follow shortly!

If you missed the Retina 2020 conference, you can watch it back on our website.

Condition-specific webinar series

Our series of condition-specific webinars, an extension of our virtual Retina 2020 programme, kicked off on Wednesday 5 May.

We were delighted to have 200 people register for the first webinar which covered the conditions retinitis pigmentosa (RP), Leber congenital amaurosis (LCA), choroidermia, Usher syndrome and retinal dystrophies.

We welcomed a fantastic panel of speakers including Ben Shaberman of Foundation Fighting Blindness, Prof. David Keegan, Dr. Alison Reynolds and genetic counsellor Jackie Turner.

We heard about genetics and genetic counselling, an excellent research overview and the clinical trials pipeline around these conditions in addition to a clinical update on the Target 5000 programme.

Dr. Alison Reynolds also presented on Charles Bonnet Syndrome (CBS) and provided us with an update on her survey created to capture information about the awareness and prevalence of CBS in Ireland. **Watch back the recording of the webinar here.**

The second webinar, held on Wednesday 2 June, covered LHON, optic atrophy and glaucoma with some fantastic panelists including Prof Jane Farrar, Prof Lorraine Cassidy and Prof Colm O'Brien.

Early July will see us host the next webinar focusing on macular degeneration, diabetic edema and retinopathy. The final webinar in the series will take place in August and will address Stargardt disease, Best disease, cone-rod dystrophy and achromatopsia.

More information on the agendas and registration for the July and August events will be communicated shortly. We would like to thank all our speakers, sponsors and attendees who make the webinars possible.

TCD and UCL researchers develop new gene therapy approach using “mini-retinas”

Prof Jane Farrar’s team at Trinity College Dublin (TCD) and Prof Cheetham’s team at University College London (UCL) have developed a new gene therapy approach that could potentially be used in the treatment of retinitis pigmentosa (RP).

The results of this promising research were published in **“Stem Cell Reports”**.

RP is a group of rare, inherited disorders that cause a breakdown and loss of the light-sensitive photoreceptor cells of the retina, leading to progressive vision loss.

RP2 is a gene that is involved in providing the instructions for cells in the retina to produce an important protein needed for normal vision.

Mutations or alterations in this RP2 gene is associated with RP diseases and can cause severe X-linked RP.

The way in which RP2 mutations cause retinal cell degeneration is still not fully understood and unfortunately animal models cannot mimic the human version of the disease well.

As part of the study the researchers wanted to explore RP2 mutations in more detail. They used human skin cells and reprogrammed them into stem cells that contain the mutated or malfunctioning copy of the RP2 gene.

These stem cells were then grown into “mini-retinas”. These are essentially three dimensional retinas grown in a dish in the lab which could mimic the retinal cell death seen in human disease.

Using a modified common virus, the scientists were able to deliver a normal, functional copy of the RP2 gene into these “mini-retinas”.

This gene was delivered successfully and was able to instruct the cells in the “mini-retinas” to produce the important protein needed for normal vision. RP2 was also able to rescue the degeneration seen in the “mini-retinas”.

Of most interest, these “mini-retinas” are capable of reproducing so many elements of inherited disease and therefore can be used to further study photoreceptor cell death.

Professor Cheetham of UCL said that that these “mini-retinas” can make it “possible for us to study in detail why people go blind and try to find ways to prevent blindness. It’s exciting that the gene therapy seems to be so effective for this form of RP.”

Retina Network Ireland update

Retina Network Ireland (RNI) is our 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 provide career-building opportunities, training and mentorship programmes to inspire greater interconnectivity amongst the community.

RNI has an excellent advisory committee composed of early to mid-career researchers and clinicians from a variety of institutions across Ireland. This committee is instrumental in advising us on what events and training workshops are relevant for this stage of their career.

To date, we've hosted numerous events as part of this network. A key highlight was the **'Overcoming Impostor Syndrome'** event that took place over Zoom in March as part of International Women's Day 2021.

There are numerous virtual events planned between now and our annual Retina conference, taking place virtually in November, with a career development event taking place as part of the conference itself. The hope going forward from Retina 2021 is that we can begin to host in-person events with networking and collaboration being at the forefront in 2022.

Meet our new Research Manager

In April we welcomed our new Research Manager, Dr Rachel Bermingham, to the team.

Rachel has a biomedical research background, having undertaken her degree in Microbiology and PhD in Immunology at Trinity College Dublin. She also holds an MSc in Immunology and Global Health from NUI Maynooth.

After completing her PhD, Rachel joined the Irish Cancer Society in July 2016, first as Research Coordinator before moving to the role of Translational Research Officer.

As part of her role, she managed the translational research funding portfolio, organised public and patient engagement events and developed the ICS public and patient in cancer research initiatives.

Rachel is particularly interested in translating research into patient benefit and developed the first research impact framework for the research department at the Irish Cancer Society.

We're sure you'll all join us in warmly welcoming Rachel to the Fighting Blindness family!

June Living Well with Sight Loss course

Our June Living Well with Sight Loss course is open for registration and available to everyone living with a sight condition in Ireland.

The free course will begin on Thursday 24 June and runs every Thursday from 11am to 3pm (with a lunch break). The course will finish on Thursday 15 July.

This online course provides advice, guidance and information on the practical and emotional supports you need to face the future with confidence.

A previous participant in a Living Well with Sight Loss course said, “Attending the course made me fully aware of the whole range of services and sports activities that are available to visually impaired people.

"Over the course of the five weeks the sessions each week hit the right note, from mobility, household gadgets, technology, sports activities, personal stories, to social protection allowances.

“Everyone on the course had different levels of vision and it was good to hear how individuals are using technology or gadgets to assist them, good tips can be picked up from listening to others.”

The course is delivered through the accessible video conferencing platform Zoom. A telephone dial in option is also available and Zoom training is provided as required.

Places are limited and must be booked in advance by contacting the team on needtotalk@fightingblindness.ie or 01 674 6496.

Volunteer Week 2021 – thank you!

It was National Volunteering Week 2021 in May and we would like to extend a huge thank you to all of our volunteers.

To mark the occasion we asked some of our volunteers to submit a few words on why they volunteer with our charity.

Jackie McBrearty said, “During lockdown Fighting Blindness was there for me, they gave me a virtual place to go so I could connect with people. Since then we've come full circle and I’m now supporting them by running groups! It’s a fantastic feeling to give back to an organisation that has given me so much.”

Cearbhall O’Meadhra added, “I currently support both the Cork and Dublin Exchange Clubs. Along with Bert Brown in Dublin and Ken Walsh in Cork, I attend to answer technical questions and occasionally take minutes of the sessions. It is great fun, actually! The questions are sometimes easy but often very challenging and this makes the whole experience worthwhile.”

Join our new gardening group – Roots!

We've launched a new online group for those of you with green fingers called Roots.

With the good weather starting to make an appearance, gardening is an excellent way of getting outdoors and keeping active. It can be of great therapeutic value in its own right.

There is a wealth of collected gardening hints and tips specific to sight loss that can be shared and we hope that by bringing similarly-minded people together, you can support and assist each other in getting your garden, whether large or small, ready for summer 2021.

This pilot group will run throughout the summer on a trial basis. Roots will meet on a Monday afternoon each month from May to August on Zoom. The next meeting is taking place on Monday 14 June at 2pm.

If you think this may be of interest to you or someone you know, please contact us on 01 674 6496 or email insight@fightingblindness.ie.

In addition to the regular monthly meetings, we've also arranged for Ron Davies from the organisation Thrive to present a talk on Monday 21 June at 2pm (over the Zoom platform).

Thrive is a UK based health organisation that promotes the use of gardening to bring about positive changes in the lives of people living with disabilities or ill health, or who are isolated, disadvantaged or vulnerable.

They have worked extensively with our colleagues in RNIB and we'd like to extend the invitation to anyone who is interested in attending this talk to contact us at insight@fightingblindness.ie or 01 6746496.

The numbers will be capped at 16 for this event so we recommend prompt booking!

Luxturna – transforming lives in the UK

Our mission at Fighting Blindness is to cure, support and empower – the founders of the organisation imagined a future where science would learn and understand the biological mechanism for how visual impairment was inherited.

They had hope that this would be possible through research, and beyond this that such knowledge would inform a treatment or cure.

Since then public support and generous donations provided the funding for researchers to investigate the retina; and an early breakthrough at Trinity College Dublin yielded the first gene to be linked to retinal degeneration.

Now some 300 genes have been identified. Ireland was at the forefront of this thinking, and now we are on the cusp of realising this dream.

We recently heard the testimony of Jake Ternent, a young man from the north of England who was the first recipient of gene therapy in the UK to treat his visual impairment. His life has been positively transformed, and his story became **headline news on the BBC**. The parents of **three year old Leo in England** are hoping that Luxturna can change their lives too.

We are within touching distance in Ireland; we have the infrastructure in the Mater Hospital and the expertise of surgeons to deliver the gene therapy Luxturna to those with the biallelic RPE65 gene – but we have yet to get the go-ahead for reimbursement.

It will be a seminal decision which the founders of Fighting Blindness, among many other stakeholders, await with the confidence that the state will do right by their citizens and approve Luxturna.

Jake Ternent on BBC News

Farewell to a dear friend and passionate advocate

Our team was greatly saddened to hear of the passing of our member and dear friend John Leonard.

John, who was living with age-related macular degeneration (AMD), was a dedicated member and passionate advocate for sight loss.

He was very generous with his time and regularly took part in our events.

He was always supportive, enthusiastic and so kind to each member of our team. He was a true gentleman and he will be missed.

The entire team would like to extend our sincere condolences to the Leonard family.

John passed away peacefully on Sunday 9 May 2021. May he rest in peace.

A summer of fundraising opportunities!

As we welcome the warmer weather, our acting Fundraising Manager Kathryn Sinnott is looking forward to a summer of virtual events.

We are so grateful as ever for those of you who have raised much needed funds by arranging Facebook birthday fundraisers, signing up for the Private Members Draw, placing collection boxes in shops, signing up for our virtual events or poignantly, leaving Fighting Blindness a bequest.

Currently, we have several events that are due to take place over the summer months.

We're so excited to be running our **Steps for Sight** virtual event again this year and we would encourage you to take part and either walk, wheel or run over the month of July.

This event proved hugely popular last year and we really hope to build on that this year.

A classical concert in aid of Fighting Blindness will take place on Thursday 24 June by Meadhbh O'Rourke and Friends. This will be a wonderful event recorded in Newman University Church and streamed over YouTube which means you can watch from the comfort of your own home! This event is free with donations most welcome.

Dublin model and former Miss Ireland, Holly Carpenter is taking part in a golf challenge to complete 18 holes in 100 shots. This is no mean feat and Holly has already raised a substantial amount of money. We wish Holly the very best with this event!

We also hope over the coming months to return to some of our signature events such as the Vision Walk and the Glendalough Trail Run!

If you would like any advice on setting up your own fundraiser, you can find some tips and ideas on our website. If you have any questions, you can give us a call on 01 678 9004 or email fundraising@fightingblindness.ie

Meadhbh O'Rourke & Friends Concert in aid of Fighting Blindness

Meadhbh O'Rourke and Friends would like to invite you to an evening of classical music.

Brought to you from the beautiful Newman University Church on Thursday 24 June at 7.30pm, all in aid of Fighting Blindness.

The concert will be streamed on the **Newman University Church's YouTube channel.**

They will have music by Steven Warner, Musical Director of the Church, as well as Bach, Muczynski, Debussy, Irish Composer Marian Ingoldsby and more!

Tickets are free but donations are encouraged. Donating through JustGiving is simple, fast and totally secure. Once you donate, they'll send your money directly to our charity.

Triple Lock Governance Award

We're delighted to announce we are certified as compliant with the Triple Lock Governance Award with Charities Institute Ireland.

Triple Lock status is awarded to charities that uphold the highest standards in transparent reporting, ethical fundraising and strong governance structures.

This recognition is the gold standard for Irish charities to offer assurances to donors, members and the general public.

We are committed to keeping our compliance under on-going review.

To achieve the Triple Lock, we:

- Maintain compliance with the Guidelines for Charitable Organisations on Fundraising from the Public.
- Prepare our annual financial statements in compliance with the Charity SORP accounting standard.
- Signed up to the detailed requirements of the Governance Code, a code of practice for Good Governance of Community, Voluntary and Charitable Organisations in Ireland.

Our vision is to cure blindness, support people living with sight loss and empower patients.

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