Visionaries

Fighting Blindness Newsletter | Winter 2019

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FIGHTING BLINDNESS
Cure. Support. Empower.

20 years of research at Retina 2019

This year we celebrated the 20th birthday of our Retina conference, an annual event bringing together the world's leading researchers and clinicians.

On Friday, 15 November, at the Davenport Hotel in Dublin we welcomed Paschal Donohoe, Minister for Finance, Public Expenditure and Reform to officially open the conference. Speaking to a packed audience, his opening address expressed his pride and astonishment at the level of innovation and expertise evident throughout the conference agenda.

Research highlights from the day included Prof John Flannery's presentation on his world-first achievement of reversing blindness in mice through gene therapy. Prof David Crabb spoke of his insightful work measuring what really matters to someone living with AMD, in particular anxieties in navigating daily life, as well as society's changing perception of AMD.

The last, and best, day of the conference took place on Saturday, 16 November, at the Radisson Blu hotel. Our Public Engagement Day is an opportunity for people living with sight loss to come together, network and meet the researchers who are searching for cures and treatments.

The day opened with an emotional address from Victoria Smurfit, actress and Fighting Blindness ambassador. Her 15 year old daughter Evie was diagnosed with Stargardts disease last year. Victoria spoke about how welcomed she felt by the Fighting Blindness community and how privileged she is to join us in our fight. Evie, presented with our Fighting Blindness Empowerment Award on the day, is an outstanding young ambassador for Fighting Blindness and a credit to our cause.

The day's agenda featured a mix of science, research and practical tools for living with sight loss. Five condition specific groups put their questions to various consultants and researchers.

Vision Sports Ireland, Need to Talk and our own Fighting Blindness team spoke about keeping fit, seeking support when you need it and how everyone has a role to play in advocating alongside us in the next general election.

Pictured: Victoria Smurfit, Paschal Donohoe, Minister for Finance and Cllr Peter Ryan

Cover picture: Victoria Smurfit, Evie Baxter and Paschal Donohoe

The RetCam arrives in time for Christmas

Up to 500 premature babies born annually at the National Maternity Hospital will now receive the most advanced sight-saving screening available, following the introduction of a new retinal camera in its neonatal unit.

The sight-saving piece of equipment, RetCam, was formally launched in November by our ambassador, Victoria Smurfit, who was at The National Maternity Hospital to celebrate World Prematurity Day.

In 2017, we partnered with the National Maternity Hospital Foundation to help raise the funds for this specialised camera. It will allow all premature babies to be screened, and have surgery performed in time to save their sight if necessary.

Eric wins Ireland's top volunteer award

It was another successful year of fundraising through our regular events such as the Glendalough Trail, the Vision Walk and the Women's Mini Marathon.

In November we hosted the Vision Gala with the Smurfit family and raised over €100,000 for the charity.

In early December Eric Beggs, one of our star volunteers, won the Volunteer Ireland award in the Health and Disability category.

To date, Eric has raised €150,000 for Fighting Blindness. Congratulations Eric and thank you so much!

Launch of IRD COUNTS

In early December we launched the results of a major research study – IRD COUNTS – a first of its kind look at the individual burden and economic impact of inherited retinal degenerations (IRDs) in the Republic of Ireland.

Total costs attributable to IRDs in Ireland were estimated to be at least €49.5 million in 2019, comprising both economic (€33.5 million) and wellbeing costs (€16 million).

Pictured: Declan Meenagh, Dr Laura Brady and Lorraine Cooke

On top of these costs, 85% of people living with IRDs reported high levels of anxiety as a direct result of their condition, and 63% said they had depression.

Currently, the evaluation of new medicines or therapies for reimbursement in Ireland does not take well-being costs into account. We presented these new findings in the hope of opening a dialogue with the Irish Government to create a new framework for assessing value for money.

Raise your voice and help us be heard in 2020

When we advocate for the latest treatments to be approved, every single member is lending their voice to our submission. When we ask for meetings with ministers, our requests go further if we have hundreds or maybe even thousands of members.

If you have a family member or friend who is living with sight loss, please encourage them to become a member. There is strength in numbers, and we'll need it next year.

In the lead up to the next general election in 2020, we will be calling on all of you to stand up with us and raise your voice. We want decision makers and politicians across the country to know about the true cost of living with sight loss and the importance of our work. We need your voice to make that happen.

Keep an eye out for emails from us and social media updates in early 2020 and join us in the fight.

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