

# Visionaries

Fighting Blindness Newsletter | Spring 2021



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**AXA Community Hero win**

**Condition-specific webinars**

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

## Welcome

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Dear members, supports and friends,

Welcome to the first Visionaries newsletter of 2021, I hope it finds you and yours healthy and well.

Although we find ourselves in another lockdown, there is hope on the horizon and I hope everyone we work with receives their vaccine in good time.

2021 got off to a great start for Fighting Blindness when Eric Beggs – our cover star – was crowned an AXA Community Hero.

The five AXA Community Heroes winners were announced by Ryan Tubridy live on the Late Late Show on Friday 29 January, with each winner securing €20,000 for a charity of their choice.

We nominated Eric for his outstanding dedication to Fighting Blindness and you can read more on page 11. Congratulations Eric!

Continuing the good news, I'm delighted to let you know we secured an RTÉ Does Comic Relief grant at the end of 2020. This grant will fund the purchase of a new system that will enable us to manage our current clients more effectively and increase our client relationship management capacity. It's great news for the Support team and our service users.

In the last edition of Visionaries I asked for your help with our Luxturna campaign. Lots of you contacted your local TD and several questions were tabled on the issue. This is a fantastic

outcome and we need to keep it up. If you haven't already, please contact your local representative and help us make this cure a reality.

Although I don't wish to end my message on a sad note, I hope you will join me in wishing our Head of Research, Dr Laura Brady, farewell.

After nearly five years leading our research department, Laura is moving onto pastures new. We're very sorry to lose a great colleague but we wish her the very best of luck of her next venture. Laura forged great relationships with everyone from members to service users to pharmaceutical partners – she'll be greatly missed.

We are currently recruiting for a Research Manager and we hope to introduce them to you in the next edition of Visionaries.

Kindest regards,  
Kevin Whelan  
CEO



## Farewell to Dr Laura Brady, Head of Research

**After nearly five years of working in and leading our research department, Dr Laura Brady, our Head of Research, has decided to move onto pastures new.**

In early January, Laura took up her new post as Programme Manager at the FutureNeuro Research Centre in the Royal College of Surgeons in Ireland.

Over the past five years, Laura has presided over five successful Retina conferences (including our first ever virtual Retina last year), a robust research portfolio and the development of Target 5000, our most ambitious programme to date which aims to identify the disease-causing gene mutation in people believed to have an inherited retinal degenerative condition.

Her dedication and superb networking skills built vital and rewarding working relationships with global pharmaceutical leaders and industry patient organisations.

Laura's greatest contribution, however, was her rapport with our many members and service users. Her personal approach was widely praised and achieving the best outcome for people living with sight loss was at the heart of everything she did.

We wish Laura the best of luck in her new role; we just know she's going to do big and brilliant things. Stay tuned for the next edition of Visionaries where we will introduce our new Research Manager.



## Retina 2020: condition-specific webinar series

**Our first virtual Retina 2020 was a huge success and showed us that, despite Covid-19 restrictions, we can still connect and engage with our audiences.**

Delivering our Retina conference virtually resulted in some key highlights; allowing more international speakers and participants, that may not have been able to attend physically, join us on the day.

However, due to this online format, we were unable to facilitate condition-specific breakout sessions, which are undoubtedly one of the highlights of Public Engagement Day (PED) each year. In response to this, we have decided to a run condition-specific themed webinar series, over Zoom, which will begin this May. Feedback from our 2020 PED showed that more than 80% of participants would be interested in attending such webinars.

Each webinar will cover the latest research and clinical trial landscape related to the various conditions as well as a brief overview of genetics and inheritance patterns. The expert panel will then address questions from the audience. We will ask attendees to submit their questions via email or phone before the event.

We hope that these webinars will provide more detailed information around specific conditions and help address any questions that were unable to be covered at our 2020 PED.

The dates for each webinar have yet to be confirmed, but they will take place midweek at 5pm to accommodate those working during the day. Sessions will be recorded and will be available after the event. Further details on this webinar series will be available soon.

[Watch our Retina 2020 PED sessions here.](#)



## International Women's Day 2021 event

**Imposter syndrome is the overwhelming feeling that you don't deserve your success – or that you do not have what it takes.**

To celebrate International Women's Day 2021, we hosted an online event on Tuesday 9 March to examine the issue and find out how we can begin to overcome it.

To help us learn more about imposter syndrome we invited two experts to speak – Aoife O'Brien and Lynda Barry.

Aoife is the founder of Happier at Work and an expert in the art of making employees happy. Her presentation examined the different ways imposter syndrome can show up in our lives. Some great takeaways for attendees included taking the time to reflect on your success and write down your achievements, something that's easy to forget in our fast-paced lives. For Aoife, the most important point to take away from her talk was to flip 'fake it till you make it' to 'believe and you will achieve'.

Our second speaker, Lynda Barry, is the founder of Lynda Barry Career Consulting. Lynda explored how we can offset imposter syndrome and mitigate the impact it might have on our CV, job applications and interviews.

She emphasised the importance of shifting our thinking when it comes to imposter syndrome. It's important that we don't feed the feelings. Instead look at the evidence; check the narrative

we tell ourselves and differentiate between facts and feelings. Lynda discussed how these feelings can impact how we present ourselves as a candidate to prospective employers and guided attendees through how they can avoid these pitfalls.

We closed our webinar with the announcement of our 2021 Early Stage Female Researcher Bursary. The Bursary is a €1000 career development award for early stage female researchers working in the area of sight loss research in Ireland. For the second year in a row, the Bursary was proudly sponsored by [its4women](#).

This year we teamed up Laura Whelan, one of our funded researchers and a social media dynamo, to piggy-back on her fantastic #ShareYourResearchSeries. We set researchers the task of explaining their research in a 30 second video and we received some absolutely brilliant entries.

Kerry Beckett, Marketing Manager at its4women, joined the event to announce the winner – [Laura Finnegan, Farrar Lab, Trinity College Dublin](#). Kerry's team felt Laura's video was exceptionally engaging and creative.

We would like to extend a warm thank you to our panelists, attendees and its4women for their support. Happy International Women's Day 2021 from all in Fighting Blindness! [Watch the event back on our website.](#)

## A transformative year for our support service

**On the 12 March 2020 we closed our office doors due to Covid-19. Our immediate concern was continuing to provide the services delivered by our support and counselling team.**

This aspect of our work had always centred on face to face interaction and we faced a significant challenge in re-working the service to adapt to the 'new normal'.

One year later and the service is as strong as ever; adapting to new ways of engaging with members and service users and continually introducing expanded and new routes to support.

We've had contact and increased involvement from individuals all over the country, with particular increases from the west and mid-west.

There's no denying that the work has been difficult and we are still very aware of the ongoing difficulties and losses that people face through the lack of in-person interaction.

However, we must also acknowledge the resilience and openness of our service users who have adapted alongside the staff team and generously share their input, feedback and suggestions on how we can all carry on together.

We've been very fortunate to have the ongoing support and dedication of our existing volunteers, with many new ones joining us over the last year to assist in the service expansion.

The spirit of support and inclusion has been exemplified by those who join our groups, both regularly and periodically. New attendees have been welcomed by long-standing members and we've been very heartened to see new friendships forged and old ones rekindled.

As 2021 progresses, we will continue to make every effort to maintain our current range of support options, whilst looking at ways to eventually return to a blended model that keeps our new online groups in place, whilst we make an eventual return to in-person services also.

### Support Service Highlights

- 63% of counselling support provided was to new clients
- An increase from 6 to 11 separate support groups
- The introduction of Zoom training for service users
- Increase of 132% in overall group participants
- 45% of support group participants were new service users

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## Foundations: a new course for young people

**This April we're delighted to pilot a new course, Foundations, that's aimed at young people between the ages of 18 and 30 who are living with an eye condition.**

The first part of this two-part course will take place over three Wednesday evenings in April. We'll cover topics such as third-level education, employment, technology, entitlements and rights.

As well as providing guidance and resources, this course will offer participants an opportunity

to meet others who may be facing similar circumstances and to learn from each other's experiences.

Foundations will aim to provide participants with a tool-kit of ideas, skills and resources to meet the challenges they face with confidence.

The course will be delivered through Zoom (which also has a dial-in option) and can be accessed by anyone in the country. If you're interested in applying or want more information, please contact us at [insight@fightingblindness.ie](mailto:insight@fightingblindness.ie)

## RTÉ Does Comic Relief grant success

**Last June, to counteract the negative impact of Covid-19 on charities across the country, RTÉ joined forces with Comic Relief to bring together the cream of Irish comedy and entertainment to raise a laugh, as well as much-needed funds.**

Over €5.5 million was generously donated by the public and The Community Foundation for Ireland opened a nationwide grant application process to distribute the funds.

The 'Demand for Digital' grant – which we successfully secured – is designed to support organisations across Ireland to adapt their existing programmes, or develop new ones, by using digital tools or online technology.

Our support team, led by Peter O'Toole, submitted an application for a grant to pay for the development of a service-specific Customer Relationship Management system to enable us to effectively manage our service users and ensure ease of access to client records for the Support team.

Since the advent of Covid-19, we have significantly increased our reach nationally. We added numerous new services and online support options, with participant numbers increasing by over 300%.

The new system will enable us to manage our current clients more effectively and increase our client relationship management capacity.

## “The choir has a special place in my heart – it’s my rock.”



**Helena Mollaghan (23) is a member of our [Visionaries Choir](#) and encourages everyone to give it a go – whether you can sing or not!**

“There’s no judgement or expectations in the choir, you don’t have to be a great singer. It’s a really warm, supportive and welcoming space.”

Helena, who has retinitis pigmentosa, joined the choir over five years ago after hearing them perform at Retina 2015. She has always loved music and felt it was the perfect first step into

the world of sight loss peer support.

“I was apprehensive and shy at my first choir meeting – I didn’t know what to expect and I was only 18. But everyone was so welcoming and I felt normal – like I belonged. It was brilliant.”

Pre-Covid-19, the Visionaries Choir met every Saturday in the Fighting Blindness office in Dublin. Now, they meet online every Saturday instead. Moving to a virtual platform was tricky but has opened up the choir to people living across the country.

“Of course I miss meeting everyone in-person but our choir master Frank Kelly and his daughter Rebecca work so hard to make it work.

“It’s easy going – a very inclusive environment. It lifts your mood and you feel so much better after it. We sing lots of different songs, from classical to pop music. It’s very therapeutic. I would encourage everyone to give it a go just once – you’ll soon be hooked!”

The Visionaries Choir is Ireland’s only choir for people living with sight loss. Singing in a choir has so many benefits – it can increase social connection, reduce stress levels, keep your brain young and improve your mental health.

The choir always open to new members and to find out more you can contact Frank on [fxjkelly@gmail.com](mailto:fxjkelly@gmail.com).

## The cure is waiting – but we will need your help

**The scientists have done their bit. The clinicians have done theirs. The pharmacists are ready. It's now down to the politicians, and us; our community, supporters and service users.**

Public opinion influences public policy - and we may need to let our politicians hear our voice.

For some people living with a mutated RPE65 gene there is the prospect of a cure waiting. It has been approved for use in the EU - and the UK.

It is now freely available to citizens in the UK through the NHS – and France, Germany, Austria, Croatia and Norway are among a growing number of countries making this first gene therapy for inherited retinal degeneration available to the small number of people who have sufficient numbers of viable cells to have

their sight restored. They are, in the main, young children.

Ireland is still considering whether this treatment should be available for reimbursement. There is a process to evaluate all new treatments for their cost and benefits – but as no other treatments exist, we must ensure that this therapy – commercially known as Luxturna – is not denied.

To ensure our campaign is robust and effective, we are asking all members, friends and supporters to contact their local public representative to voice their opinion. We have provided [draft emails and further details on our website](#) to make this as easy as possible.

We will be emailing, phoning and personally asking our members to help in the near future – a decision is expected “early in 2021”. We are ready.



# “Our donors inspire me with their stories.”

**As we begin to optimistically look forward to the easing of restrictions, our Fundraising Manager, Orla Power, reflects on fundraising in a pandemic and the power of individual giving.**

It's often said that hard times will reveal true friends – a saying that perhaps resonated with people more than ever last year. It certainly proved true for our charity, with friends across the country responding to our Covid-19 appeal last March. We're so grateful for the outpouring of support that kept our doors open and our researchers in the laboratory.

This global pandemic has put a stop to community fundraising activities but it has highlighted the power that lies in individual giving. It's easy to think that a small donation, like €4, can't make a difference but that's just not true – it all adds up and every cent makes a difference.

Over the past 12 months, our supporters have found so many different ways to raise money; they've taken on personal physical challenges, organised virtual cycles, placed collection boxes in shops, joined our private member's draw, set up Facebook birthday fundraisers or, poignantly, requested donations in lieu of flowers at a funeral.

There are too many people and stories to mention. It's inspirational and uplifts everyone in the team.



I love talking to donors on the phone and hearing their personal reasons for donating. Giving your hard earned money to charity is a personal sacrifice and not something we ever take for granted.

The challenge certainly isn't over – not for the country or our charity. We'll continue to work hard to find innovative ways to fundraise throughout 2021 and I hope you will continue to support us in our efforts.

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 my team a call on 01 678 9004 or email [fundraising@fightingblindness.ie](mailto:fundraising@fightingblindness.ie).

## Eric Beggs is crowned an AXA Community Hero

**Eric Beggs – one of our star fundraisers – has been crowned an AXA Community Hero. Eric, who is from Dundalk, has won €20,000 for our charity and €5,000 for himself!**

The five AXA Community Heroes winners were announced live by Ryan Tubridy on the Late Late Show on Friday 29 January.

AXA launched the competition last July and asked people across the country to nominate their local hero. They wanted to celebrate the unsung heroes that go above and beyond to help others and their communities all over Ireland.

We nominated Eric for his outstanding dedication to Fighting Blindness. He has supported our work for over 15 years and has raised nearly €160,000 through fundraising activities.

Eric was diagnosed with a degenerative eye condition called retinitis pigmentosa (RP) in his forties and has no eyesight left as a result. His friend Peter, who is sadly now deceased, introduced Eric to Fighting Blindness and fundraising. Since then, he has completed treks, tandem cycles, Easter egg hunts, church gate collections and more to raise money.

Thrilled by both the nomination and win, Eric said: “I’m delighted to have won, it’s hard to believe. I had to cancel all my fundraising plans last year so it’s really fantastic to be able to give

Fighting Blindness a cheque for €20,000. It’s a tough time for Irish charities and they’re doing important work.

“I’m so grateful to all my family and friends who have helped me fundraise over the years – I couldn’t have done any of it without them. Every time I asked something of them, they did it for me. It’s a brilliant community we have here. This is as much their prize as it is mine.”

Kevin Whelan, CEO of Fighting Blindness said, “Eric Beggs is an outstanding volunteer and an inspiration. We nominated him as an AXA Community Hero as we believe it is the perfect way to celebrate his illustrious fundraising career and thank him for his hard work and dedication.

“He is a deserving winner to say the very least. The money he has raised over the years has helped us to continue our mission to find a cure for blindness.”



## Holly's getting ready to tee off for charity



**Irish model, Holly Carpenter, is setting herself an unusual challenge for 2021 – learn how to play golf and break a score of 100 by this summer.**

The star will share her journey with her 96,700 followers on Instagram and has teamed up with a number of well-known brands for a series of giveaways to raise €10,000 for Fighting Blindness!

To help her succeed, the business owner has enlisted the help of The K Club's golf professional Gary Murphy. The former European Tour player will teach Holly at The K Club where he is resident Head Professional.

“It's a New Year's resolution of mine to get involved with more charity work. When I heard Evie and Victoria Smurfit's story, it hit me just

how many of us take our sight for granted. I'm delighted to be able to raise money for such an important cause.

“I've always wanted to learn how to play golf, and it's a huge bonus if I can raise money for charity. Charities have been so badly hit by the pandemic so it's important to help out any way you can. I'll be running a series of fun giveaways on my Instagram to encourage donations too!”

Fifteen year old Evie is living with Stargardt disease, which leads to reduced central vision.

We're thrilled that Holly has chosen to fundraise for Fighting Blindness! You can follow Holly's golf adventure on her Instagram page [@hollycarpenter](https://www.instagram.com/hollycarpenter) and donate via her JustGiving page: <https://www.justgiving.com/fundraising/hollys-golf-challenge>

## Get involved in virtual fundraising in 2021

**This year, until we have certainty on restrictions and vaccine rollout, we will continue to focus on virtual fundraising.**

In the summer, we will be able to reassess the situation and decide if we will be able to safely run a face-to-face event like our popular Glendalough Trail.

We're currently planning our Steps4Sight event, due to take place this July, and we will release all the details shortly. Last year our outstanding supporters raised a whopping €10,000 and we hope to raise even more this summer.

Stay tuned for more details! The event will once again be proudly supported by our corporate partner [its4women](#).

If you would like to take part in virtual fundraising – without walking or running a marathon in July – why not set up a Facebook birthday fundraiser? It's a great, and easy, way to celebrate your birthday and will raise vital funds for our work. Recent birthday fundraisers for Fighting Blindness have raised over €100 each!

If you have any questions, you can give the fundraising team a call on 01 678 9004 or email [fundraising@fightingblindness.ie](mailto:fundraising@fightingblindness.ie).



## A note of thanks to the family of Fr. Denis McHugh

**We would like to extend our condolences and sincere gratitude to the family and friends of Fr. Denis McHugh who passed away on Monday 11 January 2021.**

Fr. McHugh lived with retinitis pigmentosa (RP) and his family kindly requested mourners, if desired, to donate to our charity. Over €800 has been generously donated by Fr. McHugh's friends and family.

Fr. McHugh, Knock, Mayo and formerly of Skeaghbeg, Headford, Galway and New Jersey, died peacefully at The Queen of Peace Nursing Home, Knock. May he rest in peace.





## THANK YOU!

We would like to say a huge thank you to our corporate sponsor, its4women.ie for their continued support of our charity during a difficult time.



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

Fighting Blindness

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