RESEARCH FOUNDATION
ROYAL VICTORIA
EYE & EAR HOSPITAL

Since 1974 the Royal Victoria Eye and Ear Research Foundation has spearheaded research in the fight against sight and hearing loss.

# ACTIVITY REPORT 2018

# Contents

# The Foundation

## A history of innovation – looking to the future.

# A word from our Chairman

The Royal Victoria Eye and Ear Research Foundation has a long and proud history of being at the forefront of research in the areas of Ophthalmology and Otolarynology.

In 2018 we saw three worthy young doctors awarded the Research Foundation Medals for their achievements in research, and our Annual Grant Scheme again had a focus on studies that truly demonstrate our dedication to research which will have a tangible impact on our understanding of conditions of the eye and ultimately the care and treatment received by patients.

As the importance of medical research continues to gain a greater profile both within the healthcare sector, and with the greater public, we continue with our commitment to patients to innovate and discover.

I would like to extend our deepest appreciation to all those who supported us during 2018 and in particular, the Walls family who, as always, made a huge effort fundraising for the Dr. Eithne Walls Research Fund through the VHI Women's Mini Marathon.

Thank you.

**Mr. Jeremy O'Connor**
Chairman, Royal Victoria Eye and Ear Research Foundation

# Our work – 2018 at a glance

**3**
Research projects funded

**1,623**
Tests carried out

**553**
Inherited Retinal Disease Patients assessed

**15**
Research Study presentations at the Eithne Walls Research Meeting

**3**
Research Study Medals Awarded

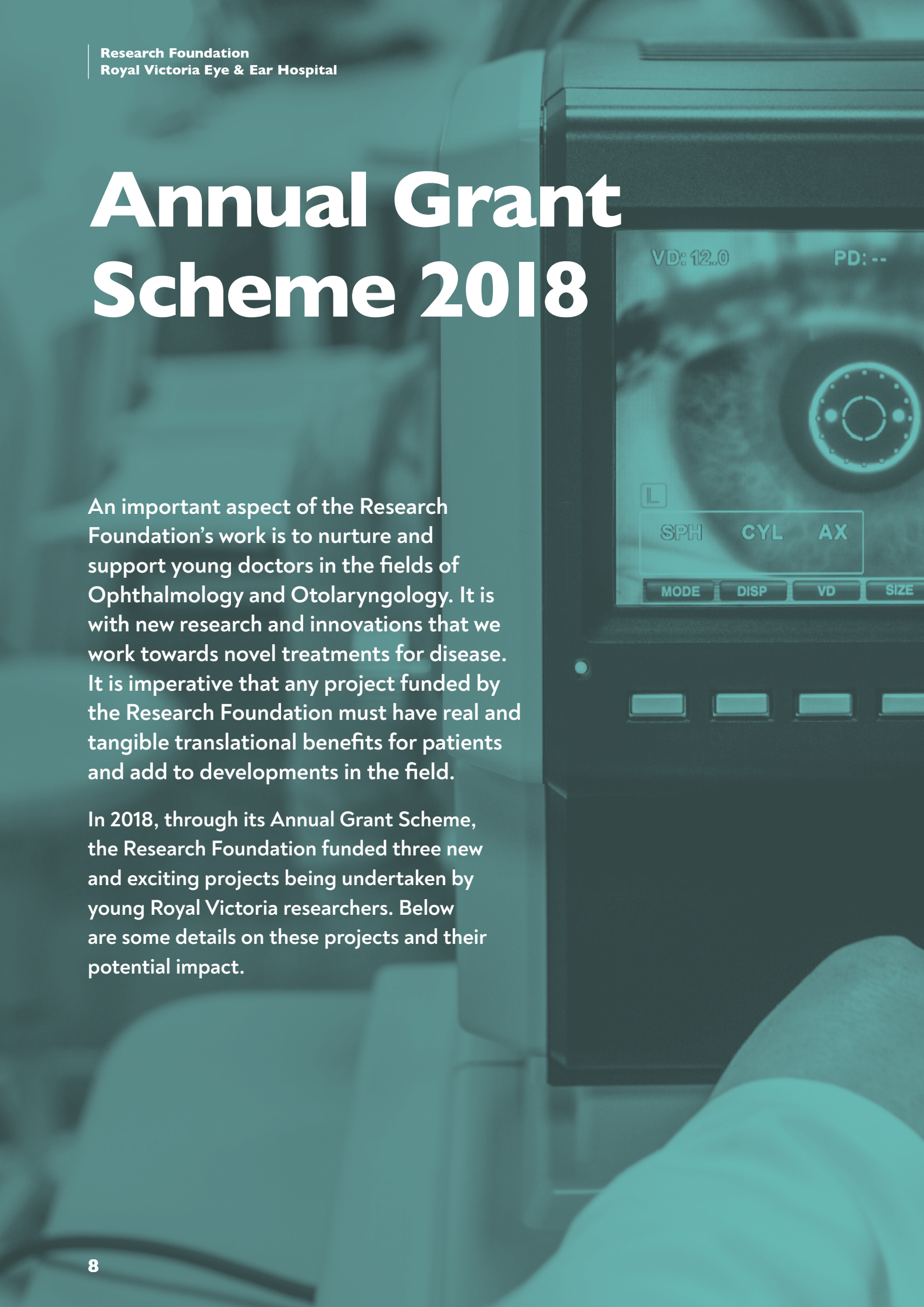
**80**
Attendees at New Frontiers Meeting

45 Years funding new clinical learning to improve patient treatment and care

# Our Aims

- To develop and champion new treatments for conditions that cause blindness and deafness.
- To initiate and support research to aid our understanding of how to treat and prevent eye and ear disease.
- Create real results in improved patient care and enhanced quality of life for patients.

# Annual Grant Scheme 2018




An important aspect of the Research Foundation's work is to nurture and support young doctors in the fields of Ophthalmology and Otolaryngology. It is with new research and innovations that we work towards novel treatments for disease. It is imperative that any project funded by the Research Foundation must have real and tangible translational benefits for patients and add to developments in the field.

In 2018, through its Annual Grant Scheme, the Research Foundation funded three new and exciting projects being undertaken by young Royal Victoria researchers. Below are some details on these projects and their potential impact.

# ‘Targeting ocular inflammation in dry eye disease with novel microRNA-based therapeutics’ Dr. Emily Greenan

**Dry eye disease (DED) is the most common patient presentation that ophthalmologists encounter, affecting 5-30% of the population aged 50 and over worldwide – this is more than that of Type II Diabetes, cancer, and heart-related problems.**

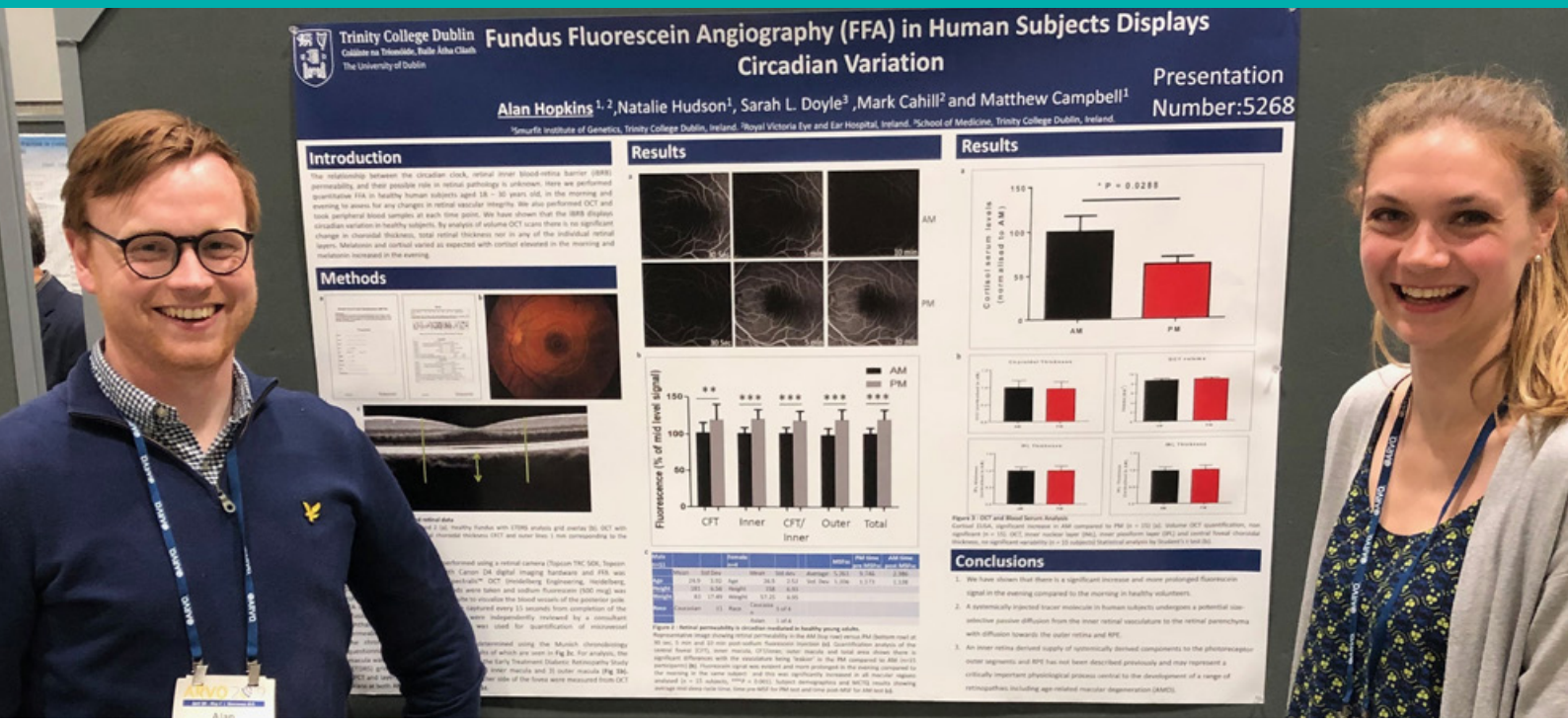
In its mildest form, DED can cause discomfort, irritation and vision distortion. In its severest form it can cause ulceration, corneal damage and loss of sight. Regardless of severity, like many other eye conditions, DED has a serious adverse effect on the quality of life of patients.

This is a study of the network of small molecules (microRNA) on the surface of the eye which can inhibit the production of cellular proteins which cause inflammation.

With what we will learn from this research, combined with a newly formulated nanocarrier formulation already developed as part of this study, it is planned to develop a antagomir, or ‘blocker’ to prevent the production of the inflammation causing proteins and also encourage ocular repair.

Dr. Emily Greenan, Dr. Emily  Ni Gabhann, Prof Conor Murphy and Dr. Christine Goodchild

# 'Circadian regulation of the retinal vasculature: A paradigm for geographic atrophy development", Dr. Alan Hopkins




Dr. Alan Hopkins and Dr. Natalive Hudson at the Association for Research in Vision & Ophthalmology

**Age-related macular degeneration (AMD) is the leading cause of central retinal vision loss worldwide. Over 100,000 people in Ireland, over the age of 50, suffer with AMD. New cases of AMD are diagnosed at rate of 7,000 per year and it is the country's leading cause of sight loss.**

The retina at the back of the eye allows you to perceive light and to convert light into a form of energy that allows our brain to form images. Essentially, the retina can be considered as an accessible part of the brain. Similar to the brain, the retina requires a constant supply of oxygen enriched blood and has an intricate network of blood vessels.

These blood vessels are easy to see when an eye doctor examines your eye. The study being proposed will allow us to determine how these blood vessels may differ in integrity at various times of the day and how this might relate to the development of the common form of blindness in the elderly, namely, age-related macular degeneration (AMD). We hypothesize that discrete changes in these blood vessels with age, may pre-dispose some people to developing AMD during their lifetime. In understanding the basic mechanisms underlying this disease, we may be better able to develop new forms of therapy.

# 'Genotype-Phenotype correations of patients with ABCA4 mutations seen at the Royal Victoria Eye and Ear Hospital', Dr. Niamh Wynne

***There are an estimated 5000 patients in Ireland suffering from an inherited retinal disease (IRD). The goal of our collaborative study 'Target 5000', through genetic diagnosis, to better enable these 5000 individuals to obtain a clearer understanding of their condition and improved access to potentially life changing therapies.***

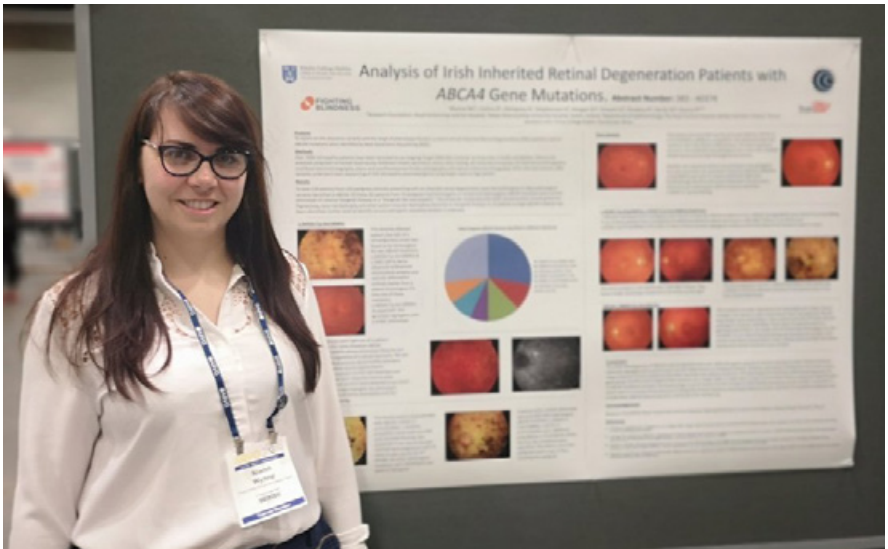
There are up to 800 people living in Ireland with juvenile onset Stargardts disease, an IRD, is one of the leading causes of blindness in under 18's worldwide and causes progressive loss of central vision.

It is most commonly associated with mutations in what is known as the ABCA4 gene. During the course of the Target 5000 study, researchers have identified many people who have mutations in ABCA4, however analysis has shown many of these do not correlate with the established pattern of well characterised Stargardts Disease previously known.

This exciting and important piece of research aims to combine the comprehensive clinical study of a patient's genotype (from the inherited gene) and phenotype (a genetic reaction to an environment) to represent the full spectrum if ABCA4 disease in Irish patients.

Studies of this type are vital to developing a greater understanding of each syndrome.

Within the context of recent licencing of Luxterna, the first genetic therapy available for any form of inherited retinal degeneration, this study, and other similar ones ongoing as part of Target 5000, aims to contribute to the body of knowledge of genotype-phenotype associations in inherited retinal degenerations, as well as contributing to patients and practitioners understanding of disease mechanisms in individual cases. This information is expected to be relevant in coming years, as more highly gene specific treatments are expected to be discovered.




Dr. Niamh Wynne presenting a poster on her ABCA4 Study at the Association for Research in Vision & Ophthalmology

# ‘Inhibiting caspase 11 in a mouse model of dry age-related macular degeneration’, Dr. Eoin Silke

**The treatment of AMD was revolutionised by the introduction of intravitreal injections, but most people with AMD have the dry type that does not respond to this. At present we can only slow the progression of dry AMD with supplements, but we have no other effective treatments.**

Dr Sarah Doyle’s research group in Trinity has been investigating the underlying causes of dry AMD for a number of years and this study was a part of that larger project. We hope to identify targets for future treatments, and test them in mouse models of AMD.

One interesting possibility is the family of enzymes called caspases. These have been studied in other contexts, but we are only beginning to understand their role in the eye. Caspases have many functions but are particularly involved in the death of cells. Our study showed for the first time that by blocking one of the caspases (caspase 11) we could reduce the retinal damage in a mouse model of dry AMD. This raises the exciting possibility that the caspases, and especially caspase 11, could be new targets for treatment in dry AMD.

> 'Dry AMD is the most common form of AMD diagnosed in older people'

**You can learn more about these studies, and all our research by visiting our website:** researchfoundation.ie

# New Frontiers in Ophthalmology

## Ocular Inflammation

### The 2018 New Frontiers in Ophthalmology took place on Thursday 7th June.

**Always an important event in the calendar year, this year's meeting again played host to expert speakers and international colleagues, focusing on advances in Ocular Inflammation. The meeting was kindly sponsored by Novartis.**

### Speakers included:

- **Dr John Fitzsimons**
  (Our Lady of Lourdes Hospital, Drogheda)
  Advances in the Diagnosis and Management of Allergy
- **Mr Barry Quill**
  (Royal Victoria Eye & Ear Hospital)
  Update on Ocular Allergy
- **Dr Monica Berry**
  (University of Bristol)
  Molecular chat: mucins, sugars and cells
- **Athanasios Vardarinos**
  Evidence on treat and extend Ranibizumab continues to build. Review of the RIVAL interim results and real-world outcomes
- **Prof Elizabeth Vandenberghe**
  (St James's Hospital)
  The challenge of managing ocular Graft versus Host disease post stem cell transplantation
- **Professor Friedrich Kruse**
  (University of Erlangen, Germany)
  New frontiers in ocular surface disorders


Prof Elizabeth Vandenberghe, Mr Barry Quill, Dr Monica Berry, Prof Friedrich Kruse, Prof Conor Murphy, Mr Athanasios Vardarinos, Ms Jane Tilley, Novartis.

# Eithne Walls Research Meeting

**Held annually, the Eithne Walls Research Meeting provides a forum for trainee doctors to present their research and clinical study work to their peers.**

**The meeting is held in memory of Dr. Eithne Walls, a Senior House Officer of Ophthalmology in the Royal Victoria Eye and Ear Foundation who was a passenger on the ill-fated flight A447 that disappeared over the Atlantic on 1st June 2009.**

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The meeting is an opportunity for trainee doctors to present their work to their peers and enhance their experience in undertaking clinical learning and research, key to continuing our work to advance education and development.

Young doctors who have taken part in the Eithne Walls Research Meeting have gone on to be part of crucial research projects bringing us closer to developing new treatments for conditions that cause blindness and deafness and broadening our understanding of how to treat and prevent eye and ear disease.

**The Research Foundation offers trainees who participate the opportunity to win 1 of 3 awards for the best presentation:**

- **Ophthalmology:**
  The Eithne Walls Medal
- **Otolaryngology:**
  The Aongus Curran Medal
- **All Specialties:**
  The Research Foundation Clinical Prize

The Aongus Curran Medal commemorates our colleague Professor Aongus Curran, the eminent ENT Surgeon and Professor of Otorhinolaryngology who passed away suddenly in August 2016.

Dr. Eithne Walls

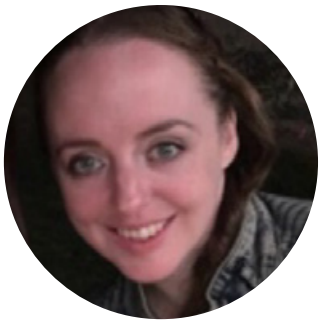
# Medal Awardees 2018

## Eithne Walls Medal

**Eoin Silke**

'Role of caspase inhibition in a model of dry age-related macular degeneration'

## Research Foundation Clinical Prize



**Dr. Aoife Lavelle**

'Quantifying the effect of flow rates on lignocaine disposition in a simulated adult airway using the Aerogen® Solo™ vibrating mesh nebulizer with the Optiflow™ system'

## Aongus Curren Medal

**Dr. Jaime P Doody**

'The Genetic, Hormonal and Molecular Determinants of Juvenile Nasopharyngeal Angiofibroma: a system review'

# 2018 Presentations

- **'The role of caspase inhibition in a model of dry age-related macular degeneration'** Eoin Silke
- **'A novel Mutation in the FLVCR1 Gene implicated in non – syndromic Retinitis Pigmentosa'** Niamh Wynne
- **'The accuracy of T2 sagittal MRI brain for diagnosis of optic neuropathy'** GM Healy
- **'Management Of Salivary Duct Stones: Our Solution To A Difficult Problem'** Natallia Kharytaniuk
- **'Intravitreal aflibercept for neovascular age-related macular degeneration in patients aged 90 Years or older: Two-year visual acuity outcomes'** Shane O Regan
- **'The Design, Manufacture and Testing of a Composite Polysialic Acid Mimetic Peptide Loaded Collagen Nerve Graft for Use in Peripheral Nerve Repair'** Jaime P. Doody
- **'Impact of Anterior Uveitis on patients: 5 year prognosis from the DUET study'** Christine Goodchild
- **'The Genetic, Hormonal, and Molecular Determinants of Juvenile Nasopharyngeal Angiofibroma: a Systematic Review'** Jaime P. Doody
- **'Phenotype correlations of patients given a diagnosis of congenital stationary night blindness (How stationary is congenital stationary night blindness?)'** Niamh Wynne
- **'Sudden Sensorineural Hearing Loss: Patterns of Presentation in an ENT Specialist Emergency Department'** Isobel O'Riordan
- **'Quantifying the effect of flow rates on lignocaine deposition in a simulated adult airway using the Aerogen® Solo™ vibrating mesh nebuliser with the Optiflow™system'** Aoife Lavelle
- **'The presentation and management of cases of retinal capillary haemangioma in a tertiary referral centre'** Ghaleb Eltaji Elfarouki
- **'Five Year Audit of IOL exchange at the RVEEH'** Brendan Cummings
- **'Sulphur Hexafluoride gas as a Tamponading Agent in retinal Detachment Surgery'** Terence McSwiney

# Target 5000 – Gateway to Vision

The Research Foundation is the primary site for the prodigious Target 5000 – Gateway to Vision project supported by Fighting Blindness. Target 5000 came out of longstanding collaboration with the Foundation and the Ocular Genetics Department of Trinity College Dublin started in the 1980's.

Along with the Mater Misericordiae Hospital Dublin and the Royal Victoria Hospital Belfast, the project aims to provide genetic testing for 5000 Irish people who have an inherited retinal condition.

Through its genetic research the Research Foundation has identified almost 3000 inherited retinal disease patients, and when identified, suitable patients are invited to be part of the Target 5000 project.

Participants in the Target 5000 project have a full retinal function work up performed in the Foundation. A blood sample is then sent to Trinity College Dublin where it stored securely. TCD Scientists perform what is known as 'Next Generation Sequencing' (NGS) on the sample. NGS is an extremely powerful platform allowing the sequencing, or reading of millions of fragments of DNA, simultaneously. If a disease causing gene mutation is identified it is then a portion is sent for repeat testing in an accredited, partner laboratory. The importance of a project like Target 5000 cannot be overstated. Identifying disease causing genes is foundational to diagnosis, treatment, and cure.

**We are proud to be part of Target 5000 project. In 2018 alone, almost 553 Target patients were seen in the Research Foundation. This project receives no statutory funding and is only made possible through Health Research Board and Fighting Blindness funding. The Foundation provides the service free of charge to patients.**

# Fundraising

Ms. Aoife Doyle and Dr. Denise Curtin

## VHI Women's Mini Marathon 2018

The ill-fated flight AF447 carrying Dr. Eithne Walls and her friends Dr. Aisling Butler and Dr. Jane Deasy, disappeared over the Atlantic on 1st June 2009.

The Eithne Walls Research Fund, established by Eithne's family, provides much needed support for the work of the Royal Victoria Eye and Ear Research Foundation and keeps the memory of Eithne very much alive in a way she would have approved of – supporting research for the prevention and treatment of eye and ear disease.

Young doctors who have taken part in the Eithne Walls Research Meeting have gone on to be part of crucial research projects bringing us closer to developing new treatments for conditions that cause blindness and deafness and broadening our understanding of how to treat and prevent eye and ear disease.

Each June Bank Holiday weekend Eithne's colleagues in the Royal Victoria Eye and Ear Hospital, friends and family, have come together to honour and celebrate her memory by running the VHI Dublin Women's Mini Marathon.

## Run for Research


Eithne's sister Kathyrn Walls (right), marathon runner and advocate for medical research.

# Thank you.

**Over the years, more than 60 runners have raised over €28,000.00 in Eithne's name.**

Eithne was a remarkable young woman, whose goal was to help, and improve, the lives of others.

2018 was no different, and we are delighted so many chose to Run for Research, raising almost €3000.00.

**Thank you to all our supporters!**

# Governance

**The Research Foundation is governed by a Board of Directors. It is the duty of the Directors to help achieve the Research Foundation's charitable objectives and to safeguard and promote its values. The Directors meet on a quarterly basis. The Directors are accountable to the Members of the Research Foundation who meet once a year at the Annual General Meeting.**

# Board of Directors

| | |
|---|---|
| Jeremy O'Connor | *Director (Chairperson)* |
| Aoife Doyle | *Director (Treasurer)* |
| Noel Horgan | *Director* |
| Mark Cahill | *Director* |
| Conor Murphy | *Director* |
| Barry Quill | *Director* |
| Julian Douglas | *Director* |
| Lorraine Foley | *Director* |
| Edward Loane | *Director* |

## Members of the Research Foundation

Patrick Dowling

William Power

Louis Collum

Jim Ruane

David Charles

Hugh Kelly

Doreen Delahunty

Company Registration Number (CRO): 514473
Registered Charity Number (RCN): 20083533
Registered Charity (CHY): 20950

# Compliance

At the Research Foundation we aim to continually improve and monitor our work and practices. Directors and staff engage with legislation, standards and codes which are developed for the charity sector in Ireland.

We subscribe to the following standards:

- **The Charities Act 2009**
- **The Governance Code**
- **ICTR Statement of Guiding Principles for Fundraising**
- **The Lobbying Act 2015**

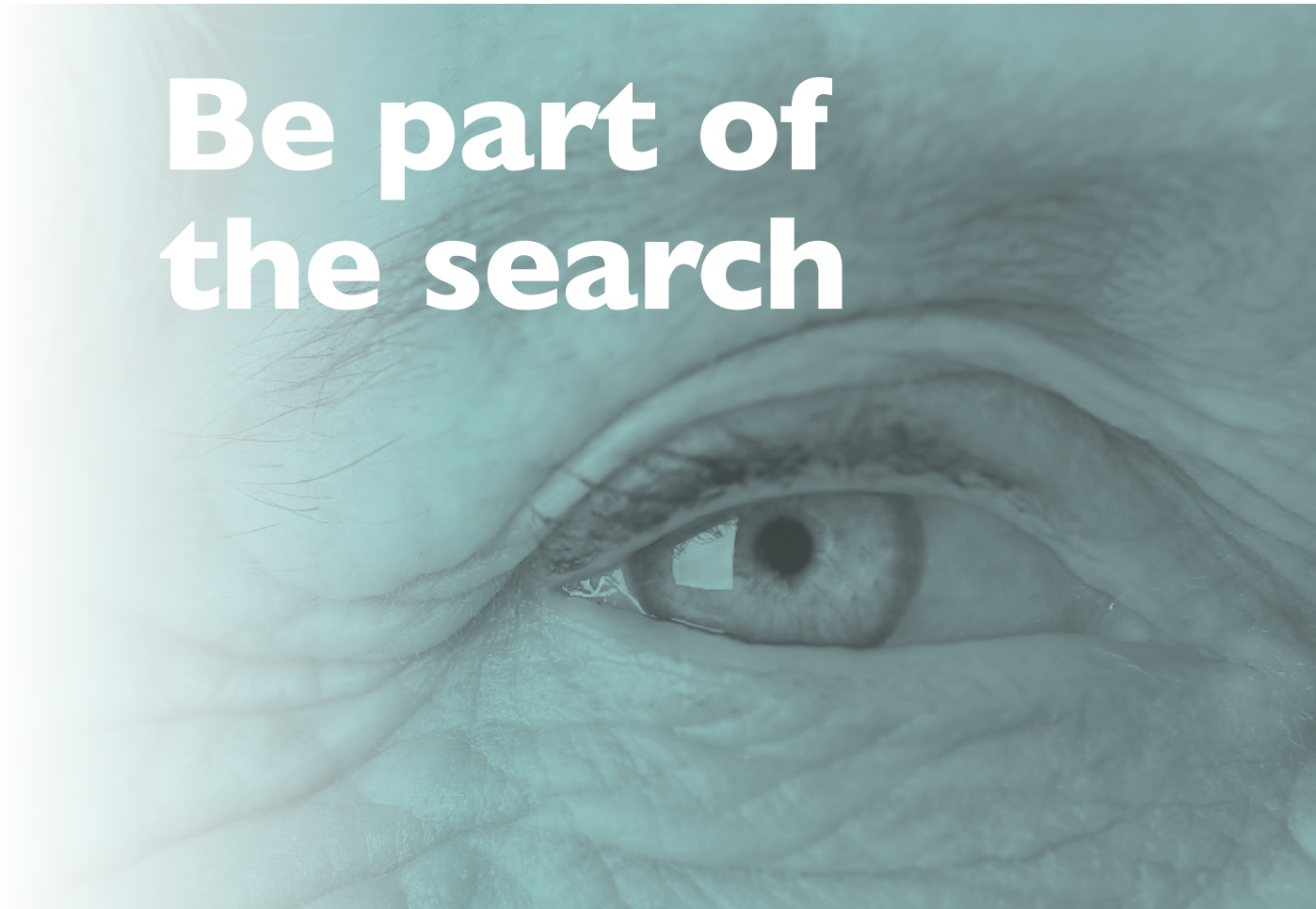
# Our Donors –
## A community with insight

### Become a Supporter

Our supporters are cornerstones of the Foundation. When you become a supporter of the Research Foundation, you are part of a community that is inspired by the impact research has both in the present, and for future generations. Think of the vast chasm between health outcomes now, and in the past – supporters of research have paved the way forward.

We promise to use all donations as they are intended – to fund research and innovation in the fight against sight and hearing loss. The Research Foundation is a registered charity and adheres to the Guiding Principles of Fundraising.

Our Donor Charter outlines our commitment with our donors – a relationship based on respect and appreciation.



## Become a Patron

Be a cornerstone of the Foundation

Patrons are the cornerstones of the Research Foundation. They enable us to continue our research programmes and push forward in achieving our goals:

- To develop and champion new treatments for conditions that cause blindness and deafness.
- To initiate and support research to aid our understanding of how to treat and prevent eye and ear disease.
- Create real results in improved patient care and enhanced quality of life for patients.

Patronage is open to both individuals and groups. It is important to us to honour and recognise the kind contribution of our patrons, without whom the our work would not be possible.

Please contact us for a discussion about our work and learn more about our Patron Circles.

## Research Foundation Business Network

A Partnership with Purpose

The Research Foundation understands a partnership with your company is a collaboration. We will work with you to develop a charity partnership which has a real impact on your company, staff and community.

There are many ways in which we can work together, from sponsorship and patronage, to staff engagement.

Joining the Research Foundation Business Network, indicates your company's wish to make a difference through research and innovation, the benefit of which will be felt now and in the future.

## Leave a Legacy

Look ahead and leave your mark on the future

Leaving a legacy is an amazingly generous act and testament to your support of the work of the Research Foundation and understanding of the positive and far-reaching impact of medical research.

There are many ways in which you can make a gift to the Research Foundation in your will, and if you would like to know more, we have developed a legacy information pack to assist you. Please contact us if you would like to receive a copy of the information pack.

**Please visit us at www.researchfoundation.ie to learn more about our work and become part of our community.**

Royal Victoria Eye & Ear Research Foundation
Adelaide Road, Dublin 2
Tel: 01 6393630

***"Alone we can do little, together we can do so much"***

– Helen Keller

***"An investment in knowledge always pays the best interest."***

– Benjamin Franklin

# We welcome your feedback on our performance via any of the contact points provided.

## Contact us:

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**F** 01 6614 670