

Fighting Blindness

**Patient – Partners in research for the treatment
of chronic Age-Related Eye Disease**

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Vision and Values

Our Vision:

- **A world where all sight loss can be prevented or cured.**

Our Mission:

- **Fighting Blindness will find treatments and cures for sight loss through world-leading research, while providing support to those affected directly and indirectly.**



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Blindness**

Key facts about Blindness

- 314 million people are visually impaired worldwide, 45 million of them are blind.
- 82% of all people who are visually impaired are age 50 and older.
- Females are more at risk at every age, in every part of the world.
- The number of people blinded by infectious diseases has been greatly reduced, but age-related impairment is increasing.
- Increasing numbers of people are at risk of age-related visual impairment as the global population grows and demographics shift to a higher proportion of older people.
- About 85% of all visual impairment is avoidable globally.



About Fighting Blindness

Established by six families in 1983.

- **Patient-led organisation**
- **Board is made up of ten volunteers.**
- **Six board members including chairman are patient representatives with two business people.**
- **Funded 16 world-class research projects since its establishment.**



Continued ...

- Provides a unique professional counselling service *Insight Counselling Centre* based in Dublin with plans to roll out nationally
- Irish representative of AMD Alliance International & Retina International
- Represents Ireland also in Retina International, EPF and EURORDIS
- Established the 'Retina' platform for researchers and clinicians to work together and share their knowledge.



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Eye conditions we hope will benefit from our patient led research ...

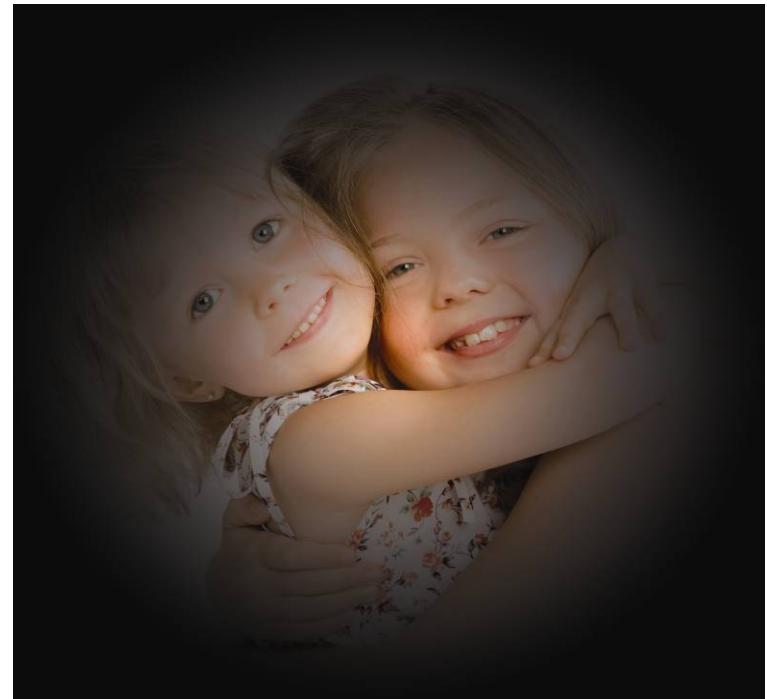
- **Stargardt's Disease**
- **Ushers Syndrome**
- **Leber's Congenital Amaurosis**
- **Leber's Hereditary Optic Neuropathy**
- **Early Onset Macular Degeneration**
- **Diabetic Retinopathy**



Conditions we research...

Retinitis Pigmentosa (RP)

- **Genetically Inherited.**
- **Between 3,500/5,000 in Ireland.**
- **Leads to tunnel vision.**
- **Gradual deterioration of sight over unspecified time.**
- **Passed down through the generations but can also occur sporadically where no family history exists**



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Conditions we research...

Age-Related Macular Degeneration (AMD)

- Loss of sharp, central vision. Leading cause of blindness in the western world.
- 1 in 10 people over 50 affected (approx 80,000 in Ireland).
- Multiple risk factors including: diet, smoking, fair colouring, hypertension and genetics.
- World Health Organisation considers AMD to be one of the most significant threats to global



Global partnerships of patin research



**Getting our facts
straight !**



White Paper

Information gathering and analysis across several fronts:

1. Patient and caregiver focus groups
2. Patient survey
3. Wet AMD working group



Wet AMD working group objectives

Discuss, understand, and address:

- Patient and caregiver needs, concerns
- Economic and social impact of wet AMD
- AMD treatment patterns
- Chronic nature of wet AMD
- Policies and practices that support wet AMD patients

Goals

- **Increase understanding globally that wet AMD is a chronic disease in some countries viewed as acute**
- **Ensure early intervention and treatment for persons at risk for or living with wet AMD**
- **Provide an integrated model of care for persons living with wet AMD**
- **Pursue preventative interventions**
- **Encourage vigorous research efforts to close the gap on unmet patient needs through continued R&D**



Wet AMD is a chronic disease

The Reality

Wet AMD is a persistent, progressive, and incurable disease that must be assessed and treated on a regular, ongoing basis – sometimes as often as monthly – if treatment is to be effective and sight loss arrested or restored.

The Need

Recognition of wet AMD as a chronic disease will help improve access to appropriate care and ensure appropriate reimbursement for that care, reducing sight loss and minimizing the economic burden placed on societies throughout the world by visual impairment.

Wet AMD is a chronic disease

The Challenge

In some countries treatment for wet AMD is reimbursed as if for an acute disease and treatment is provided on a short-term or ad hoc basis, decreasing access, limiting patient outcomes and potentially endangering sight.

Call to Action

Wet AMD must be recognized as a chronic disease to ensure that :

- All patients have access to early intervention; regular, planned, proactive treatment; and integrated care,**
- Research is ongoing for improved treatment options**

Wet AMD impacts quality of life

Persons living with wet AMD experience:

- Difficulty performing daily activities
- Social isolation
- Higher than normal rates of depression
- Twice the risk of premature death as those not visually impaired
- Increased risk of falls and related hip fractures
- Premature admission to nursing homes



It is not just sight that is affected,

Development of AMD and lack of understanding of the condition among care givers and professionals can lead to depression and other mental issues



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Regular treatment is essential

- **Persons living with wet AMD have best outcomes when they have regular clinical assessments and are treated with regular, planned, proactive therapy**
- **Repeated treatment may be necessary, as often as monthly**
- **New compounds in development may have sustained treatment impact; research into delvive systems requiring fewer treatments and visits to doctor**



Why do we need more research with treatment options becoming available?

- Improve drug delivery systems
- Reduce the frequency/dossage
- Examine the opportunity of combination therapy
- Discover drugs that can reverse the disease process
- Improve efficacy of intravitreal drugs
- Standardise treatment
- Preventative measures



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Patient led Research

We are seeing the results!



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Patient led research @ TCD

- **This project is working on the development of molecules capable of opening and closing the Retina Blood Barrier to allow drugs taken orally and dissolved in the blood, access the inside of the eye Many drugs that act on the inside of the eye need to be injected because the cells that line blood vessels inside the eye don't allow drugs to pass through.**
- **The cells are tightly cemented together with proteins.**
- **These proteins can be inhibited by small molecule so if they are not produced drugs can 'leak' into the eye where they take effect.**



Continued...

- **The molecules are produced by a harmless virus introduced into the eye, and their release can be controlled by using a chemical switch.**
- **The initial findings of this research are promising, and show that it is possible to selectively open channels in the Blood Retina Barrier, and that this opening is reversible.**



Patient led AMD research @ WIT

- **Macular Pigment (MP) protects the eye from Age-related Macular Degeneration.**
- **This project examined if the distribution of MP in different parts of the eye is important in disease onset. It particularly focuses on the issue of obesity and its impact on the distribution of nutrients**
- **Components of MP are obtained from the diet so results of this study clearly showed that those affected with obesity do not distribute MP effectively and this can increase the chances of developing AMD.**
- **We know now that a healthier lifestyle can lead to immediate benefits, delaying the onset of the condition**



Tilda Study

- **Public private partnership research TCD/St. James Hospital Dublin**
- **10,000 cohort of people over 50**
- **Detail the process of diseases affecting the over 60s**
- **Ophthalmologists have access to volunteers to measure macula**
- **Longitudinal study**

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Patient Led Research is Showing Results

Patient driven research in conjunction with key stakeholders must be a priority!!!!

Now !



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The Value+ Project and Meaningful Patient Involvement



Patient participation in research – an international outlook

Challenges

- Attitudes and prejudices -
- Limited knowledge
- Language and terminology barriers (health literacy)
- Lack of resources
- Administrative practices

Strengths and Benefits

- Integration of researchers' theory expertise with patients' real-world knowledge and experiences
- Balance scientific excellence with social and cultural relevance
- Higher trust and acceptance of research results
- Promotion of research results by patient organisations (enhanced visibility)



Good Practices

- Meaningful involvement as a specific objective
- Patient involvement as a continuum
- Clear vision of expectations, roles and abilities
- Genuine partnership on an equal basis
- Resources
- Appropriate Communication

Value+ Core Publications

Series of Tools:

- to enable patients to become more involved in EU funded projects including research projects (Value+ Toolkit)
- for project promoters and coordinator to acquire more skills to enable them to facilitate in practice (Value+ Handbook)
- a series of policy recommendations looking at linking research project outcomes with patient – centred policy development
- a database of patient organisations in all EU Member States



Looking to the future

Advances to Patient Research practice over the next decade will require:

- Patients – equal and respected research partners**
- Establishing clear links between patient practices, processes, and core elements to health outcomes**
- Establishing the effectiveness of Patient Research in achieving health outcomes**
- Increasing studying and training opportunities for Patient Research**
- Achieving greater support for Patient Research approaches among funders and institutions**



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Take-home message

Research WITH
VS
Research ON
patients

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Thank You for Listening

Go raibh maith agut

