

Fighting Blindness

**Working with Stakeholders for a better Quality of Life
for those affected by Sight Loss In Ireland**

EUCERD – October 25, 2011, Luxemburg

Avril Daly – Fighting Blindness / Genetic & Rare Disorders Organisation

Fighting Blindness Cure. Support. Empower.

What Fighting Blindness is all about

- **CURE**



- **SUPPORT**



- **EMPOWER**



Introduction

- Diagnosed with Genetically Inherited Rare Condition Retinitis Pigmentosa at 23 through eye exam for driving test – No family history
- Asked by Ophthalmologist if I liked dogs because I would need a guide dog within three years – No Cure
- Very lucky to be referred to Dr. Paul Kenna a specialist in rare retinal degenerations at dedicated research centre
- Told living in the best city in the world for Retinal Research he mentioned Fighting Blindness
- Rest is history



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Darkness to light and hope

**Ireland and Irish people
play a pivotal role in the
world in research into
treatments and cures
for blindness**

Research is patient led !

**Gave up my job in
publishing to work for
Fighting Blindness**



The Fighting Blindness Story

- Started in 1983 as a group of families affected by blindness getting together for support.
- Now a global leader in the search for cures and treatments for genetically inherited and age-related forms of blindness
- Researchers in TCD funded by Fighting Blindness located the first known gene responsible for causing Retinitis Pigmentosa (since then over 100 other genes have been discovered)
- Genetic research successful due to the fact that Ireland had so many large families making it easier to trace the genetic course of the disease here.
- Since this first project in 1989 FB has continued to progress the knowledge we have of degenerative eye conditions and progress the research into treatments and cures.



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CURE



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Eye Conditions we are concerned with

- **Retinitis Pigmentosa**
- **Leber's Hereditary Optic Neuropathy**
- **Usher Syndrome**
- **Leber's Congenital Amaurosis**
- **Stargardt's Disease**
- **Glaucoma**
- **Age-related Macular Degeneration**
- **Diabetic Retinopathy**



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Research Activities

- **Since FB formed in 1983 we have funded 40 research projects in universities and colleges in Ireland, with one in the UK**
- **We also advocate for sustainable infrastructures to expedite the development of therapies**
- **We lobby to ensure equitable access to these therapies when they become available**



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Gene Therapy



Stem Cells and Cell Therapy



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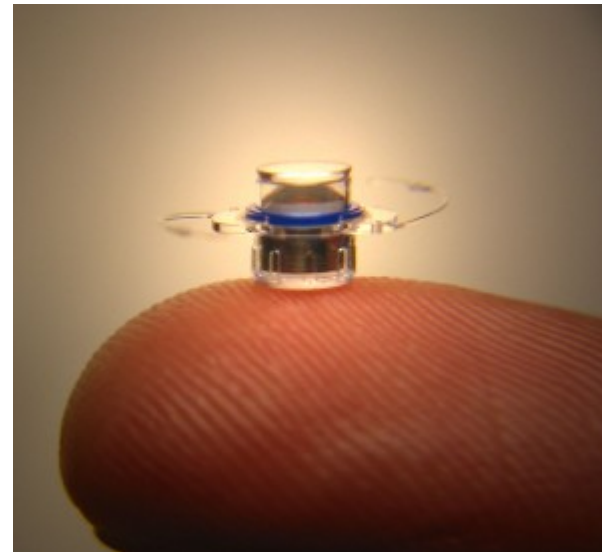
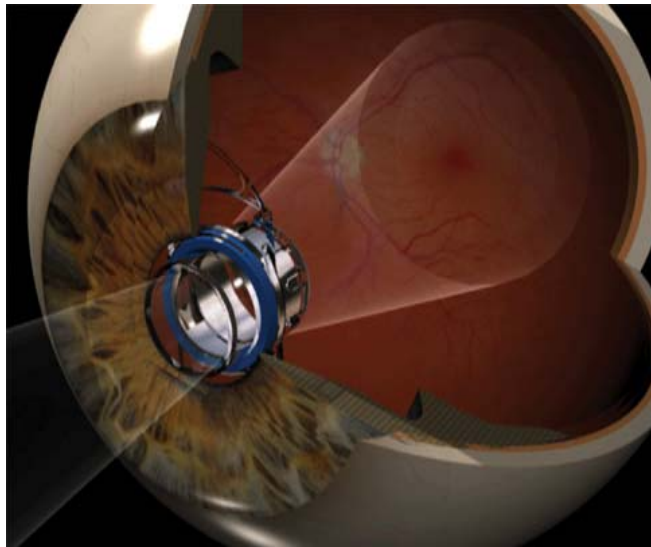
Epidemiology & Population Studies



Novel Drug Therapies



Retinal Implants



Today's Research; Tomorrow's Cures

“When Fighting Blindness started 28 years ago there were only questions. Today, they have the tools for a cure in their hands.”

**Paul Norton,
Fighting Blindness Member**



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SUPPORT



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“Losing your sight is like losing someone you love. It’s like a part of your heart is gone. You have to adapt both emotionally and mentally”

**Gerry Kerr,
Fighting Blindness
Board Member**



Support

- Being diagnosed as 'going blind' is a deeply traumatic experience. Patient testimonies include the emotional response of denial, anxiety, insomnia, agoraphobia, displaced anger, grief, depression, & finally acceptance and change
- Fighting Blindness recognise that while developments in research have been phenomenal in the last couple of years that patients today are still going blind and need immediate support. This is why we established Insight Counselling Centre.
- Fighting Blindness is unique in that it offers free professional counselling and psychotherapy of the highest clinical standard to individuals with visual impairment, their families and significant others.



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Counselling Services Available



- Individual therapy
- Family Member Group Therapy
- Spouse Group Therapy
- Outreach Patient Workshops
- Regular monthly group meeting in Cork
- Weekly support at the Royal Victoria Eye & Ear and Mater Hospitals, Dublin.
- Phone appointments also available



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EMPOWER



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Empowering Patients through EU Outreach

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- In 1984 FB became a member of Retina International and in 1988 established GRDO in Ireland to advocate for a National Centre for Medical Genetics
- In the 90s FB began to investigate what was happening with groups concerned with Rare Diseases in the EU and how activities in MS could apply to our national systems
- Joined EURORDIS in 1997
- Built coalitions in Ireland to advocate for funding and care pathways for people with rare, genetic, chronic and age-related diseases



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Nothing About US Without US! (EPF)

- To be informed actors in the search for treatments for unmet medical needs patients need to work as equal partners with all stakeholders
- As policy relating to health and medical research often has its origins at EU level – we must be active on two fronts **EU/Nationally**
- Patient involvement in policy development is now seen as a vital element in gaining consensus on issues that will ultimately affect them and their families

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Bringing it all back home...



IPPOSI

- **Based on the Original EPPOSI model of stakeholder involvement established in Ireland as IPPOSI in 2002 launched as secretariat in 2007**
- **Building Dialogue Between Patients' Organisations, Science and Industry**
- **IPPOSI remains a Patient-led group, consensus-building approach on issues regarding access to new therapies and treatments for unmet medical needs**
- **Develop dialogue and consensus between all interested parties**
- **Provide a platform to discuss policy, legislation, regulation, ethics, and social issues surrounding the development of therapies, diagnostics and medical devices in Ireland**



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MRCG

- **The Medical Research Charities Group (MRCG) is an umbrella group of medical research and patient support charities formed to represent the joint interests of charities specialising in restoring health through medical research, diagnosis and treatment and, where possible, the prevention of disease.**
- **A core belief of the group is that today's health research is tomorrow's healthcare**
- **The MRCG believes that patient organisations should lead and stimulate critical medical research needed by patients, and will provide leadership and support to charities in Ireland that are engaged in medical research.**



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GRDO

- **The Genetic and Rare Disorders Organisation (GRDO) acts as a national alliance for voluntary groups representing the views and concerns of people affected by or at risk of developing genetic or other rare disorders**
- **The Genetic and Rare Disorders Organisation acts as a watchdog in relation to legislation concerning disability to ensure that the rights of people with genetic or other rare conditions are protected**



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Working together to enable NP Development

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- **GRDO Member of EURORDIS CNA**
- **Learned about EUROPLAN at Annual Conference in 2008**
- **No Irish Ministerial representation at the time**
- **Approached then Irish Minister for Health to agree to host EUROPLAN Conference – Agreement 2009**
- **As voluntary group GRDO approached Secretariats of IPPOSI and MRCG to support execution of event**
- **Multistakeholder organising committee established April 2010**



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Irish EUROPLAN – Farmleigh House



158 Attendees at Irish EUROPLAN

- **Patient representatives and their families**
- **Representatives from the Health Ministry (DoH)**
- **Medical representatives including: clinicians, nurses, psychotherapists, counsellors, paramedics**
- **Representatives from educational bodies**
- **Scientists**
- **Industry**
- **Media**

Outcomes

- **Establishment of a Steering committee of Experts to work on NP development by Minister for health in April 2011**
- **Four patient representatives on steering group**
- **Towards 2013 Taskforce formed by patient groups GRDO/MRCG & IPPOSI formed to support the steering group**
- **Taskforce includes, patients, medics, industry, researchers and education experts**
- **Hoped first public consultation on NP for RD, late Spring 2012**



Ultimately

Through Engagement with EURORDIS and EU groups Rare Disease patients in Ireland can now contribute to development of a workable National Plan that will ultimately lead to:

- **Empowerment of Patients through the establishment of a National Centre for Rare Disease that is linked internationally, directing and supporting existing and newly diagnosed patients to the most up to date information**
- **Shorten the diagnostic odyssey through the coordination of Centres of Expertise – in Ireland diagnosis in some conditions can take up to 21 years**
- **Advocate for development of sustainable research infrastructures to expedite the search for therapies for unmet medical needs**
- **Establish fair and equitable access to medicines in Medicines for Rare Diseases when they become available**



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Where to find us

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Thank You



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