



**Fighting
Blindness**



Annual Report

April 2007 – March 2008

***Fighting Blindness -
An Irish solution to a world problem.***

Highlights of 2007/2008



Des Cahill RTE pundit (left) and champion jockey Ruby Walsh, Gold Cup Ball 2008



Morocco Trek Group

Channel 6 presenter Jenny Buckley (left) and TV3's Andrea Hayes at the Venetian Carnevale.



Japan Trek Group

Front cover: scientist photo courtesy of Aspect Photography; our thanks to the Everest trekkers and Fighting Blindness members Kelle and Paul Norton. Edited by Hilary Makin. Design by Patricia O'Brien.

The Work of Fighting Blindness

Fighting Blindness is working to find cures and treatments for diseases affecting the back of the eye – the retina – which lead to your sight gradually disappearing over time.

Many of these conditions are inherited and affect an estimated 65,000 adults and children in Ireland and 40 million worldwide. One condition we are working to cure – age-related macular degeneration (AMD) - is the leading cause of blindness in the western world and is set to reach epidemic proportions as more people live longer. We are also world-leaders in research into Retinitis Pigmentosa (RP) – a condition causing severe tunnel vision.

Currently there are few or no treatments for people with these diseases. However Fighting Blindness is now developing therapies, drugs and devices to help prevent sight-loss or treat these devastating conditions.

Fighting Blindness funds research projects at six universities around Ireland and is developing the Fighting Blindness Vision Research Institute (FBVRI) to speed up our quest for cures.

Being diagnosed with a degenerating eye condition can be absolutely terrifying for an individual and also their families, even if they knew there was a hereditary risk factor. Dramatic changes must be made to their lifestyle and that of their families, friends and colleagues.

Fighting Blindness also provides Ireland's only professional counselling service – the Insight Counselling Centre - for people with visual impairments and their families.

Please read on to find out about our research and counselling achievements or visit www.fightingblindness.ie for more information.



Normal Vision



*Vision of someone
with Retinitis
Pigmentosa*



*Vision of someone
with AMD*

About Fighting Blindness

Fighting Blindness funds world-leading research into cures and treatments for blindness. It also provides Ireland's only professional counselling service for people with visual impairments and their families.



Fighting Blindness member Pat Traynor (left) with Chairman Dave Waldron at the charity's 25th anniversary celebration.

For 25 years, Fighting Blindness has been at the forefront of efforts to understand the causes, prevent the progression, and work towards treatments and cures for blinding degenerative conditions. This year has seen much of that work begin to pay dividends.

An emotional highpoint of the year was hearing Prof Robin Ali, of London's Moorfields Eye Hospital, present his groundbreaking work on gene therapy at a recent Retina International congress. The project was part-funded by Fighting Blindness.

After receiving the gene therapy treatment, Steven Howarth from England was shown successfully navigating a darkened room - something he could not have achieved before. A standing ovation, the first I have experienced at a scientific congress, was enough to bring a lump to the throat and a tear to the eye. At last, therapies are in sight and we are delighted to welcome Robin and Steven to speak at this year's AGM.

This breakthrough is just the tip of advances yet to come. However, to ensure that the work continues, we need to keep the pressure on. Fighting Blindness has moved to expand its research by launching its own Vision Research Institute (FBVRI) which has received Science Foundation Ireland approval and will hopefully result in significant financial support.

It has been a remarkable 25 years. From the early days of dealing with an unknown, mystery illness we are now benefiting from a wealth of knowledge from research and are close to therapies being available.

On behalf of the Board of Directors, I wish to express a heart-felt thanks to our hard-working staff, our generous supporters and pay a special tribute to Michael Griffith, our out-going CEO, who has led the organisation to where it is today. The Board is strengthened by his presence.

The years ahead present us with challenges but also the promise of great rewards.
There is light in sight.

Dave Waldron
Chairperson



Patrick Quinn, Chief Executive.

The year ending March 2008 was a landmark 25th year for Fighting Blindness. I am delighted to report that our net income was increased to €1,498,000 - up nearly 50% on last year's income of €1,022,000.

Research expenditure at €828,059 was the highest ever - a five-fold increase over last year's €166,000. At year end we were funding nine research projects in Ireland and one in the UK. This is a great achievement and I would like to thank my predecessor Michael Griffith for his dedication and hard work over the years to enable this to happen.

This year has produced a major scientific breakthrough with the announcement of the results of the world's first gene therapy for inherited blindness by Professor Robin Ali and his team at University College London.

Since being appointed as CEO in spring 2008 I have been delighted to see another breakthrough in the establishment of our Fighting Blindness Vision Research Institute (FBVRI) at Dublin City University. We are confident that this initiative will speed up the search for treatments and cures for retinal degenerative conditions.

Under the leadership and direction of Professor Michael Comer, the Institute has just received recognition from Science Foundation Ireland as an eligible research body.

This is a first for a charity in Ireland and a huge achievement for the team.

Fighting Blindness has also finalised a major investment in Genable - a Campus Company in Trinity College that grew out of our research there. The investment of €600,000 over three years will significantly expedite the development of their suppression/replacement gene therapy. Michael Griffith will sit on the board of Genable on behalf of Fighting Blindness.

I am proud of the ongoing work of our Insight Counselling Centre and we are working hard to expand this service across Ireland in the coming year.

I would like to thank all the staff at Fighting Blindness for their hard work and efforts that have made this a successful year.

I would also like to say a sincere thank you to our many and varied supporters who continuously surprise us with their hard work and generosity in donating the funding to take our research to the next level. We consider our donors and fundraisers a part of our extended team and would like to thank you on behalf of all our members, researchers and staff.

Patrick Quinn
Chief Executive



Prof Michael Comer, Head of Research

Fighting Blindness is the only charity in Ireland funding research to prevent, treat and cure blindness. During 2007/08 we invested €850,750 in research – five times more than the previous year and our highest investment ever.

Through 2007/08 we:

- 1) were funding 10 individual research projects;
- 2) established our own Fighting Blindness Vision Research Institute; (FBVRI)
- 3) agreed to fund a start-up company to generate new gene therapies and begin clinical trials for blindness.

1) Research Project

Fighting Blindness was this year funding 10 research projects in universities and colleges, covering five themes: a) gene therapy, b) new drugs to slow or prevent damage to eyesight, c) nutrition and eyesight, d) artificial retina implants and e) stem cell therapies. Below is an update on each of the areas.

Gene therapy to cure blindness

In 1989 our funded researchers were the first in the world to identify the damaged gene responsible for 'Retinitis Pigmentosa', a condition leading to severe tunnel vision. These scientists have made significant progress working to switch off the fault in the gene, and replace it with a new, functional gene, delivered in a harmless virus injected into the back of the eye.

Fighting Blindness also helped to fund a breakthrough in this area led by Professor Robin Ali at University College London/Moorfields Eye Hospital. This team works on a different gene causing a condition called Leber's Congenital Amaurosis (LCA) and had the first successful gene therapy trial. They proved gene therapy is safe and effective for eye conditions. This breakthrough paves the way for our Trinity team to get to clinical trials more quickly.

“This is truly an exciting time for blindness research in Ireland.”

Prof Ali said: “It is very encouraging to see that this treatment can work... however, it is important to emphasise that gene therapy is still an experimental treatment not yet generally available to patients.” In spite of the caution expressed in Prof Ali's remarks, this result places a milestone for the prospect of gene therapy not only for blinding conditions but other genetic disorders that cause many other types of disease and suffering. Fighting Blindness is very proud and pleased to have supported Prof Ali's efforts by helping to fund his research programmes.

Drugs to slow or prevent damage to eyesight

Our funded researchers in University College Cork are investigating known and new medicines to protect the retina from damage. They are investigating the biochemical processes which cause the damage and have discovered that a special protein may be involved.

Nutrition and eyesight

Age Related Macular Degeneration (AMD) is a devastating condition which causes central vision to disappear. Our funded researchers in Waterford Institute of Technology are studying the macula – the centre of the retina responsible for seeing fine detail, daylight and colour vision. They know the macula is protected by macular pigment, which comes from the diet. Now they are measuring the pigments present in the macula and how it's distributed in different people's eyes to understand more about the link between AMD and macular pigment.

Artificial retina implants

Researchers at the Tyndall National Institute for electronics, University College Cork, are developing a microchip which they hope to implant to replace a damaged retina. The team is currently developing a coating for the implant, to make it compatible with living cells.

Stem Cell

Stem cells are special cells which can develop into any type of cell – heart, brain, kidney, eye, etc. Our team at University College Dublin is studying zebra fish. The genetic make-up of these fish is just 2% different to humans. They are also able to ‘regrow’ retinal cells. The UCD team is looking at how the fish are able to do this and how it might be eventually applied to humans.

2) The Fighting Blindness Vision Research Institute

Following a strategic review of our research activities, Fighting Blindness has taken the unprecedented step to found its own Vision Research Institute (FBVRI). We are the first charity in Ireland to do this. This institute will be based at the National Institute for Cellular Biotechnology in Dublin City University and will directly employ scientists and staff to carry out research. The institute will serve to consolidate our research activities, and act as a nucleus for building up a national and international research network.

3) Investment in Campus Company

Fighting Blindness has agreed to invest in a campus company – Genable - that has grown out of research we funded in the genetics group at Trinity College over several years. Genable aims to convert their scientific findings into treatments for patients within the next few years. Fighting Blindness will be represented on Genable’s Board of Directors.



Fighting Blindness Researcher

“We have established ourselves not only as a national, but global leader in what we do and a lot of that is credited to Fighting Blindness and the seed-funding the charity has provided us with. Our research group wouldn’t exist without Fighting Blindness so the charity really needs people’s support.”

Dr John Nolan, Deputy Director of the Macular Pigment Research Group, Waterford Institute of Technology.



Mary Lavelle and guide dog Star

This is the sixth year of operations at the Insight Counselling Centre and the work of the Centre continues to grow. Over 280 clients have availed of the services provided. Families, couples, parents, children and individuals are using the Centre to meet a variety of needs including psychotherapy, counselling support, information and guidance. Our plans to extend the service throughout the country are gradually being put in place. Those wishing to avail of the counselling service in their area can do so by contacting the Insight Counselling Centre directly.

This year, we continued to offer:

- a telephone support service to those unable to travel or those seeking a more immediate response.
- monthly support group meetings in Dublin and Cork (our thanks to the Irish Guide Dogs for providing the venue for the Cork meetings).
- support services at both the Royal Victoria Eye and Ear Hospital and the Mater Hospital in Dublin each Wednesday and Thursday morning, respectively.

New initiatives this year included:

- welcoming a new trainee psychotherapist to the Centre. A fellow Fighting Blindness member, John Delany is completing his third year of the Graduate Diploma & MSc programme in Integrative Counselling and Psychotherapy.
- a new therapy group in Dublin which has been both successful and beneficial to those taking part. At the request of the group members, it will continue to run throughout the coming year.
- a three-day support training course to a sister organisation in Dubai.

We would like to express our appreciation and thanks to Dolores Leahy who continues to give generously of her time each Thursday morning at the Eye Clinic in the Mater Hospital.

We would like to thank the Health Services Executive for their continued financial support, without which this service could not be provided, our corporate sponsors and all those who take part and support Fighting Blindness events. Your contribution is invaluable to the development of this vital service.

Mary Lavelle
Head of Counselling



Avril Daly, Head of Public Affairs

The 25th Anniversary year for Fighting Blindness brought new initiatives, new collaborations and new faces to the organisation. It has always been our belief that a united voice is a strong voice. Here are some of the groups we lead or work with, and the highlights of 2007/08.

Medical Research Charities Group - a collection of 24 charitable organisations promoting medical research in Ireland. Fighting Blindness was successful in receiving matched-funding grants through the MRCG/Health Research Board joint funding scheme.

European Platform for Patients Organisations Science and Industry (EPPOSI) and the Irish Platform for Patients Organisations Science and Industry (IPPOSI) - promoting co-operation between patient groups, science, government and industry to inform European and national policy on developing treatments and access to them for patients.

The European rare disorders group Eurordis designated February 29, 2008, as the first 'Rare Day for Rare Disorders'. Fighting Blindness is a member of the Genetics and Rare Disorders Organisation (GRDO) as several of the conditions we are working to cure are classed as rare disorders. GRDO held an awareness day on February 29 and called on the Government to implement a national plan for rare disorders.

Vision Impaired Service Providers Association (VISPA) – Fighting Blindness, NCBI, The Irish Guide Dogs for Blind, and St Joseph's Centre for the Vision Impaired came together to launch VISPA. The group advocates for better services and funding for those affected by sight-loss in Ireland, launching a directory of services and website (www.vispa.ie).

We continue to work internationally with **Retina International** and the **AMD Alliance**, as well as the **All Ireland Retinal Research Network (AIRRN)**, which Fighting Blindness initiated in Ireland. These networks ensure our members have access to up-to-the-minute information on global research developments and allow us to promote and stimulate research to speed up the development of treatments.

In January Hilary Makin joined our team as Communications Manager and has been working hard on repositioning the brand and promoting the organisation, our events and campaigns. We are developing our website and published our 'Visionaries Newsletter' for our members and supporters.

Avril Daly
Head of Public Affairs

Fundraising Report



Dell employees in Dublin donate the €1,000 proceeds from their foosball table to Fighting Blindness.



The Morning Crew from Dublin's 98 swapped their studio for the skies to raise €2,000 in their 'Leap for Leap Year' skydive, February 2008.



Former rugby international and Fighting Blindness ambassador Shane Byrne joins FB-funded scientist Theresa Heffernan to launch the Wicklow Challenge.



Champion jockey Nina Carberry and Ted Walsh at the Fighting Blindness Hennessy Gold Cup Ball, February 2008.

The gross income of €2,500,933 and net contribution of €1,498,544 to March 2008 was nearly a 50% increase on the previous year. This was a very good result and a huge thanks to all our supporters throughout the country for making this possible. Our challenge is to build on this success going forward particularly in the difficult economic climate.

The National Raffle was the main income generator for the year. Close to 19,000 people participated and raised €786,383. In addition our Private Members Draw is going from strength to strength with 2,500 members generating €187,000 at year end.

The sixth annual Gold Cup Ball took place at the Four Seasons Hotel, Dublin, and raised over €130,000 which was a huge success. A big thank you to the committee for all the hard work and also to all those who attended for their generosity.



Dublin women's mini marathon participants for Fighting Blindness.



Fighting Blindness trekkers draw closer to Everest base camp.



Fundraisers taking part in the Fighting Blindness Wicklow Challenge over 75km.



Model Karen Fitzpatrick launches the Gold Cup Ball with a dress from the Powerscourt Design Centre which was auctioned at the event.

Our overseas treks continued strongly. This year we completed successful trips to Morocco, Japan and Mt. Everest Base Camp. As a result of the tremendous fundraising efforts from our loyal band of trekkers and their supporters we raised over €430,000. We look forward to their continued support as we create treks in new and exciting destinations.

Our many supporters as ever gave of their time and energy to raise funds for us by organising church gate collections, running marathons and mini marathons, jumping out of airplanes, trekking over mountains and bogs and organising or attending scores of events.

Thank you!

Upcoming Events 2009

February – **Fighting Blindness Gold Cup Ball**

Book your table at our spectacular gala ball. Now in its sixth year, this annual fundraiser is the place to be seen and attracts fantastic support from the horse racing community and corporate sector.

Spring – **Join our Jungle Adventure!**

Trek Panama with Fighting Blindness to help fund our research projects and counselling centre. Explore pristine rainforests as you follow old Inca trading routes from the Pacific to the Atlantic coast.

September – **3 days, 2 nights, 1 serious challenge!**

Get together your team of two or four people to take part in our fun Wicklow Challenge. Choose from the ambitious 70km runners' route or the more leisurely walkers' route which includes fun challenges along the way.

October Bank Holiday Weekend – **Light For Sight weekend**

The Fighting Blindness national awareness and fundraising initiative. Help us put the spotlight on sight loss conditions and raise money for our research into cures.

Autumn – **The Fighting Blindness AGM**

Autumn – **Everest Base Camp Expedition**

You could take part in the challenge of a lifetime in this, our second, trek to Everest. Take in the most breathtaking scenery imaginable and gain an insight into the life and culture of the people of Nepal.

For more details about these events:

Call: +353 1 709 3050

Email: fundraising@fightingblindness.ie

Visit: www.fightingblindness.ie



Photos: Everest Trek, Gold Cup Ball, Panama Trek

BOARD OF DIRECTORS

Patricia Burke
Stephen Farrelly
Jacqueline Hall (resigned March 2008)
Frank Kelly
Colette McNamee
Dave Waldron - Chairman
Tony Ward

STAFF

CEO's Office:

Patrick Quinn, Chief Executive; Anna Moran, PA to Chief Executive

Research:

Prof Mike Comer, Head of Research; Dr Patrick Corley, Research Manager; Rosie Begley, PA to Head of Research

Public Affairs/Press Relations:

Avril Daly, Head of Public Affairs; Hilary Makin, Communications Manager

Fundraising / Events:

Clodagh Ryan, Fundraising Events Manager Elaine Leinaweaver, Campaign & Database Manager; Sue Ryan, Events Coordinator; Barbara Cahill, Community Events Coordinator; Emma Horgan, Corporate Development

Accounts:

Deborah McCann, Financial Controller; Padma devi Ramalingam, Senior Book keeper

Insight Counselling Centre:

Mary Lavelle, Counselling Psychologist; Ann Cooke, Counselling Administrator

Bankers: AIB Bank plc.,
37/38 Upper O'Connell Street,
Dublin 1.

Auditors: BFGD Chartered Accountants,
1 Castlewood Avenue,
Rathmines,
Dublin 6.

Solicitors: M.J. Kennedy & Co.,
Parochial House,
14 Main Street,
Baldoyle,
Dublin 13.

STATEMENT OF FINANCIAL ACTIVITIES

(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31st MARCH 2008

	2008 €	2007 €
<u>Incoming Resources</u>		
Incoming Resources from Generated Funds		
Voluntary Income	384,338	299,189
Activities for Generating Funds	2,099,189	1,455,316
Investment Income	<u>17,406</u>	<u>2,320</u>
<u>Total Incoming Resources</u>	<u>2,500,933</u>	<u>1,756,825</u>
<u>Resources Expended</u>		
Costs of Generating Funds	1,002,389	735,687
<u>Net Incoming Resources</u>	<u>1,498,544</u>	<u>1,021,138</u>
Charitable Activities	1,597,050	827,281
Governance Costs	<u>10,703</u>	<u>19,099</u>
<u>Total Resources Expended</u>	<u>2,610,142</u>	<u>1,582,067</u>
Net (Outgoing)/Incoming Resources	(109,209)	174,758
<u>Balance Forward at 1st April 2007</u>	<u>299,076</u>	<u>124,318</u>
<u>Balance Forward at 31st March 2008</u>	<u>189,867</u>	<u>299,076</u>

There are no recognised gains or losses other than those disclosed in the Statement of Financial Activities for the year.

BALANCE SHEET AS AT 31st MARCH 2008

	<u>2008</u> €	<u>2007</u> €
<u>Fixed Assets</u>		
Tangible Assets	24,995	17,074
Financial Assets	<u>1</u>	<u>1</u>
	<u>24,996</u>	<u>17,075</u>
<u>Current Assets</u>		
Stocks	2,996	3,288
Debtors	114,273	166,669
Cash at Bank	<u>1,129,217</u>	<u>613,593</u>
	<u>1,246,486</u>	<u>783,550</u>
<u>Creditors: Amounts falling due within one year</u>	<u>(1,081,615)</u>	<u>(501,549)</u>
<u>Net Current Assets</u>	<u>164,871</u>	<u>282,001</u>
<u>Total Assets Less Current Liabilities</u>	<u>189,867</u>	<u>299,076</u>
<u>Financed by:-</u>		
Accumulated Reserves	<u>189,867</u>	<u>299,076</u>

The information above has been extracted from the financial statements of Fighting Blindness for the year ended March 31, 2008. The auditors have reported without qualification on those financial statements which are available upon request from Fighting Blindness.

The Financial Statements are presented in a form to comply with the State of Recommended Practice (SORP) for charities.



**Fighting
Blindness**

Fighting Blindness

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Insight Counselling Centre

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Company Information

Fighting Blindness is a company limited by guarantee.

Registered company number 109625.

Registered charity number CHY6784.

Registered address is 1 Christchurch Hall, High Street, Dublin 8, Ireland.

