



Fighting Blindness Annual Report April 2010 - March 2011

Fighting Blindness is an Irish charity funding world-leading research into treatments and cures for blindness.

Registered Charity No. CHY 6784
Patron: President of Ireland, Mrs Mary McAleese

www.FightingBlindness.ie



**Fighting
Blindness**

Cure. Support. Empower.



Michael Griffith
Chairman

Fighting Blindness invests €503,815 in Research

The period April 2010-March 2011 was not without its challenges as the country continued to deal with an uncertain economic outlook. However, it was a year in which Fighting Blindness restructured to ensure we could meet our considerable financial targets. This, coupled with breakthroughs and developments in the progress of our research in Ireland, gave our organisation every reason to be optimistic as we embarked on another year.

The outcome to the end March 31 2011 was a positive one with a net contribution of €1,316,529 (2009/2010 €1,650,206).

Our determination to fund and facilitate world-leading research into treatments and cures for blindness continues unabated with an investment of €503,815 in the past year.

“Our determination to fund and facilitate world-leading research into treatments and cures for blindness continues unabated”.

We are strengthening our relationships with our research partners in Ireland who continue to prove that they are global leaders in their field. In January 2011, we were extremely excited to learn that a potential treatment for the dominant form of Retinitis Pigmentosa (RP) developed by our team at Trinity College, Dublin received Orphan Drug Designation from the European Medicines Agency (EMA). This was the first time an Irish team received designation for a gene therapy product and was a watershed moment in the search for a therapy. As we enter the exciting era of clinical trials, we are further developing our relationships with international partners and will leave no stone unturned in finding treatments and cures as soon as possible.

Many of our research projects reached their completion stage in the past year. We are now working on a new research strategy that will consolidate the work we funded over the last three decades and take us to the next stage. We have secured funding for two new projects in the area of genetics and cell therapy. With these exciting initiatives, we will also embark on an ambitious but necessary campaign to genetically profile our population base in order for us to establish a register of people in Ireland with inherited retinopathies. This is an

essential step in expediting the clinical trial process.

I cannot over emphasise the importance of the commitment of our members, volunteers and supporters all over the country in helping us reach this stage. I would like to acknowledge the exceptional work of our Board, staff and researchers over the past year to keep Fighting Blindness on track and focused on its goals.

The Insight Counselling Centre also continues to grow, assisting over 380 clients and creating new outreach opportunities. Families, couples, parents, children and individuals use the Insight Counselling Centre to find support and guidance through individual psychotherapy and group sessions.

There is no doubt that we are living through extraordinary times and we anticipate that the fundraising climate will remain volatile in the coming year. However, we will continue to do all that we can to generate the much-needed funds to achieve our goal of curing and treating sight loss in the shortest possible timeframe.

By working together, our future will be a bright one.



Tony Ward at the Sporting Luncheon



Trekkers reach Everest Base Camp

“The progress of our science from the laboratory to the clinic is sustained by the on-going commitment of our members, volunteers and friends. You make the journey to a cure possible”.



Avril Daly
CEO

Today, over 100,000 people in Ireland are affected by degenerative eye conditions like Retinitis Pigmentosa, Stargardt’s Disease, Leber’s Congenital Amourosis, Age-related Macular Degeneration and Diabetic Retinopathies. We are confident that our research will eventually lead to life-altering treatments for people with these rare, genetic, age-related and chronic eye conditions.

In the past year, we witnessed an acceleration of research into these conditions, many now nearing the clinical trial stage. For the first time, we can see what potential treatments will look like. They are gene therapies, pharmaceutical compounds, cell-based treatments, bionics and lifestyle changes.

While we are optimistic about the potential of clinical trials, we will continue to support basic research in academic institutions developing new approaches to saving and restoring sight. Our research will undertake to screen our population to discover new genes and will aid in the development of compounds to treat blindness, find better ways to regenerate retinal cells and refine the mechanisms for drug delivery.

To enable this work we are developing specific indicators to expedite the development of our research through five pillars:

1. Genes and Gene Therapy
2. Cells and Cell Technology
3. Epidemiology and Population Studies
4. Bionics and Implants
5. Bio-Pharmaceutical Products

Fighting Blindness will equip Irish researchers with the tools needed to be the innovators and visionaries of the future. In the coming years, we will continue to invest in the development of up-and-coming scientific and clinical researchers through the **Retina** Platform and Research Communications Group. At the same time, we will collaborate with Irish and international organisations to ensure that structures are in place to allow people with sight loss to benefit from therapies resulting from this research.

Fighting Blindness currently chairs the Genetics and Rare Disorders Organisation (GRDO) and represents Ireland on the Board of the European Organisation for Rare Diseases (EURORDIS). The Minister of Health, Dr James Reilly, appointed us to become a member of a steering group representing patients affected by rare diseases in the development of the National Plan for Rare Diseases in Ireland.

We are at the forefront of development of European policy on healthcare through our presence on the Board

of the European Patient Forum (EPF). We represent the views of Irish patients through a unique patient-led partnership, the Irish Platform for Patients’ Organisations, Science and Industry (IPPOSI). This platform provides a structured way of facilitating interaction between patients’ organisations, scientists and industry (and where possible state agencies) on policy, legislation and regulation around the development of new medicines for unmet medical needs in Ireland. Fighting Blindness works closely with the Medical Research Charities Group (MRCG) to advocate for sustainable funding and better infrastructure for the development of medical research in Ireland. We also represent Ireland in Retina International and the AMD Alliance International on issues relating to vision research and eye health.

As a patient-led charity, we work to bring people affected by sight loss and researchers together. Since our founding in 1983, our mission has been to work with the scientific community by investing in, supporting and enabling those working to confine sight loss to the history books.



Anna Moran
External Affairs Manager

In the past year, Fighting Blindness restructured the research department, developing an External Affairs Manager role to oversee the research portfolio, manage scientific communications and develop advocacy and public relations initiatives. In September 2010, Prof Mike Comer retired after 3.5 years of contributing to the strategic development on the Fighting Blindness research programme.

External Affairs Report

Europplan Conference

In January 2011, Fighting Blindness participated in the Irish Europplan Conference at Farmleigh House. Europplan is an EU funded initiative that commenced in 2008 to develop recommendations on the establishment of national plans for rare diseases in each member state by 2013. Avril Daly was appointed by the European Organisation for Rare Diseases as an advisor to the Europplan Initiative for Ireland and the UK.

The conference was organised by the Genetics and Rare Disorders Organisation (GRDO), the Medical Research Charities Group (MRCG) and the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI) along with industry, scientific and medical representation.

Board member, Tony Ward spoke at the research workshop attended by senior members of the Department of Health and the HSE. Topics discussed during the workshops covered the development of research into rare diseases, fair and equitable access to treatments for rare diseases, the establishment of centres of excellence in the area of rare disease and patient empowerment.

Dr John Devlin, Deputy CMO of the Department of Health, stated that Europplan was an important initiative and a starting point for multi-stakeholder discussions on the development of a National Plan. As a result of the conference, Minister of Health, Dr James Reilly established a Rare Disease Steering Group charged with developing recommendations for Ireland's national strategy. Avril Daly, CEO, is on the multi-stakeholder task force.



Avril Daly, CEO Fighting Blindness, Josie Godfrey, NHS UK, Prof Andrew Green, NCMG, Prof Eileen Treacy, Mater Hospital at the Europplan Conference in Farmleigh House.

Research Report

€582,322 was invested in research during 2010/2011.

Dublin Centre for Clinical Research

Fighting Blindness, in association with the Dublin Centre for Clinical Research (DCCR), is working towards the establishment of a gene therapy trial in Leber's Congenital Amaurosis (LCA). The first step is the development of a national clinical register of persons with Early Onset Severe Retinal Degenerations (onset of severe visual impairment before five years of age). We held several successful clinics during the year that move us closer to the establishment of a register that will form the basis of the clinical trial.

Retina 2010 Conference

Over 100 people attended the annual Retina Conference in November 2010 at Dublin's Radisson Blu Royal Hotel. A distinguished panel of Irish and international speakers attended the event including Prof Gregory Hageman (Utah), Prof John Ash (Oklahoma), Prof Pete Coffey (London) and Prof Tom Cotter (Cork).

Through presentations, exhibitions and interactive dialogue, we demonstrated the very latest developments in retinal research. Some of the topics discussed concerned developments in the use of stem cells for retinal conditions, breakthroughs in drug delivery systems, new medical applications investigating potential for RP treatment, gene therapies and the development of clinical trials in Ireland.

The Retina Conference will take place again in November 2011, bringing together scientists, clinicians, healthcare professionals and patients to accelerate the search for treatments and cures for retinal degenerations.

Research Project Updates

Genes and Gene Therapy

Gene therapy platform technology for dominant retinitis pigmentosa receives Orphan Drug Status

– Genable Technologies Ltd

Fighting Blindness made a substantial investment in Genable Technologies Ltd, a company developing new gene medicines to treat dominant genetic diseases based on the pioneering work of Prof J Farrar, Dr P Kenna and Prof P Humphries at Trinity College, Dublin. In December 2010, Genable's first gene medicine was granted Orphan Drug Designation by the European Medicines Agency.

On the molecular pathology of retinal degradation caused by mutations within the IMPDH1 gene

– Prof Pete Humphries, Trinity College, Dublin

Published in Human Molecular Genetics in 2008 and 2010, this research is investigating the causes of RP10, accounting for 5% of all cases of dominant retinitis pigmentosa.

Gene therapy for Leber's Hereditary Optic Neuropathy using AAV2 to transfect the NDI1 gene

– Prof Jane Farrar, Trinity College, Dublin

This research is exploring ways of modulating the symptoms associated with LHON by delivering a gene that provides energy to the compromised cells in the eye.



We held several successful clinics during the year that move us closer to the establishment of a register that will form the basis of the clinical trial.

Cells & Cell Therapy

The development of cell-based therapies for the treatment of photoreceptor degeneration in mouse models of retinitis pigmentosa

– Prof Jane Farrar, Trinity College, Dublin

The focus of this project is to develop retinal stem cells to one day restore vision. A variety of techniques are being investigated to develop and integrate the transplanted retinal stem cells into retina.

Directing retinal stem cells to become functionally integrated cone photoreceptors in host retinas

– Dr Breandan Kennedy, University College Dublin

The group used zebrafish as a new model of inherited blindness to identify drugs that may restore visual function in some cases. They will now determine which drugs are most effective and safest, and which genetic diseases are most responsive.

Exploration of stem cell-based therapies for retinal degenerations

– Prof Jane Farrar, Trinity College, Dublin

Obtaining stem cells with the potential to repopulate a particular tissue in the body is a great challenge. The focus of the research project is to define which of the hundreds of miRNAs present in humans are important for the differentiation of retinal stem cells.

Potential of umbilical cord derived cells for retinal stabilisation and repair

– Dr Reaz Vawda, Trinity College, Dublin

Dr Reaz Vawda worked for two years on this project. The work he started is continuing and there have been several publications as a result of the project.



Population Studies

Spatial Profile of macular pigment in relation to risk for age-related macular degeneration

– Prof Stephen Beatty, Waterford Institute of Technology

This research investigated factors that determine the macular pigment level, a reduction of which causes the loss of central vision. The project also looked at the association of weight loss and changes in lutein and zeaxanthin (the pigments that make up macular pigment in the eye). The study indicates that weight loss in overweight individuals may increase macular pigment levels and reduce their risk of AMD.

Other

Consultant & Associate Professor of Research

– Robin Ali, Associate Professor of Research

Prof Robin Ali has been an invaluable resource as we develop our research strategy and set in place strong governance structures for the organisation. In addition, Prof Ali addressed our members at the 2010 AGM and provided advice regarding research developments globally.

AMD: validation in murine model of novel approaches to suppression of retinal neovascularisation

– Prof Pete Humphries, Trinity College Dublin

This project is investigating a non-invasive form of drug treatment for AMD, that will deliver therapies directly to the site of disease in the retina. This work was published in the Proceedings of the National Academy of Sciences (USA) in 2009 and in EMBO Molecular Medicine in 2011. EMEA-mandated safety and toxicology studies are now in preparation.

Counselling Report

Despite the current economic climate, we intend to extend the services provided by the Insight Counselling Centre nationwide. Our monthly support group meetings in Dublin and Cork are ongoing and we are beginning to organise regional information sessions with counselling, research and fundraising staff. Thank you to the Irish Guide Dogs for providing the venue in Cork for Fighting Blindness support group meetings.

This year, we continued to provide a support service at both the Royal Victoria Eye and Ear Hospital and the Mater Hospital in Dublin each Wednesday and Thursday morning respectively. We wish to thank Dolores Leavey who generously gives her time at the Mater Hospital Eye Clinic. Her presence there is very welcome by the patients receiving diagnosis of eye conditions.

We would also like to thank our corporate sponsors for their continuing support of the Insight Counselling Centre. In particular, we wish to express our appreciation to Dublin Bus for their funding towards the purchase of much needed technical equipment.

We are very grateful for the continuing financial support of the Health Services Executive. Without their contribution, we could not offer this unique and essential service.

We also wish to thank everyone who supports Fighting Blindness and participates in our events. Your contribution makes it possible to respond to the needs of people experiencing sight loss.



Mary Lavelle
Head of Counselling

The Insight Counselling Centre provides psychological help and support to individuals and families affected by sight loss.

The Insight Counselling Centre is Here for You

The Insight Counselling Centre provides psychological help and support to individuals and families affected by sight loss. Over 380 people have availed of our face-to-face counselling service. Many others contact us by telephone or email to request information, guidance and links to related services.

The Insight Counselling Centre provides a safe place for many people during a difficult time. To ensure privacy, the Insight Counselling Centre is located at 4 South Great George's Street in Dublin, separate from the main Fighting Blindness office. For those unable to travel, we also provide a telephone and Skype service.

If you would like further information or would like to speak to someone in confidence, contact the Insight Counselling Centre at +353 1 674 6496 or email insight@fightingblindness.ie.



Anne Cooke and Star at the Sporting Luncheon



Elaine Leinaweaver
Head of Fundraising

Fundraising Remains Strong with Significant Support from Members and Volunteers

We are delighted to report that through the dedication of so many members, friends and supporters, Fighting Blindness had a successful fundraising year despite the challenging economic climate. Our funding needs remain high but with your support we know we can raise the funds necessary to advance and facilitate vital research to find treatments and cures for sight loss.

Treks and Challenges

Fighting Blindness started off the year with an exhilarating trek to Transylvania in association with the Diabetes Federation. Sixteen dedicated trekkers climbed through Bucegi Mountains and picturesque terrain of this hidden corner of Europe. It was a challenging week enjoyed by all involved.

Later in the year, six serious adventurers came together for a once in a lifetime trip to Everest Base Camp that took their fundraising and training to great new heights. A special thank you to Stuart Steele and Denis Kelly of Silverhill Foods who raised above and beyond their fundraising targets.

Many of our supporters preferred to stay closer to home, participating in the two-day Mourne Mountain Challenge in September and the inaugural Fighting Blindness Glendalough Trail in October.

Over 200 people travelled to Wicklow for the 15km off-road race, securing its place in the fundraising calendar for 2011.

Fighting Blindness was represented at many events throughout the country including the Dublin and Cork Mini Marathons, Dublin City Marathon, Newry City Half Marathon, Galway Half Marathon, Belfast Marathon and Clonakilty Marathon. A special thank you to Marina O'Neill who walked the Dublin Half Marathon with a guide in a fantastic time of three hours and thirty minutes. Thanks to everyone that pounded the pavement to help us find treatments and cures for blindness.

National Raffle and PMD

Fighting Blindness is indebted to thousands of members and supporters across Ireland taking part in the National Raffle and Private Members Draw, two of our biggest fundraising initiatives. We would also like to recognise the support of the Gowan Group who helped provide a star prize of a Peugeot 107 car to two lucky winners of the Private Members Draw. If you would like to be in with a chance to win, contact the Fundraising Department or visit www.FightingBlindness.ie.



Top Left: David Norris, Avril Daly and Patricia Wallace at the Sporting Luncheon; Bottom Left: Everest Decathlon Team; Right: Dublin Ladies Mini Marathon Team

Volunteer Led Fundraising

Our volunteers play a fundamental role in supporting Fighting Blindness. Their willingness to help and the time they give us is invaluable. We are grateful to all of our volunteers who organised events from dance marathons to pub quizzes, sold books, managed counter-top collection boxes or held tournaments in aid of Fighting Blindness. Our volunteers came out in force through the wintery months of November and December to sing carols and sell Christmas cards on our behalf. A special thanks to Frank Kelly, Eric Beggs and Tony Ward who played a significant role in their home counties of Offaly, Louth and Monaghan respectively to recruit volunteers and organise church gate collections.

Signature Event

The Fighting Blindness Sporting Luncheon is a highlight on the calendar and very popular among guests. We are indebted to the racing and rugby communities who support us each year. In particular we would like to recognise Mr Des Cahill, Mr David Casey, Mr Mick Galwey and Mr Shane Byrne for their dedication to this event over the years.

We would also like to give special thanks to the committee who helped organise the luncheon including, Mrs Jane Byrne, Mr Colm Cronin, Mrs Patricia Wallace and Mr Tony Ward.

Thank you to everyone that supported Fighting Blindness and our many activities over the last twelve months. Every single person has played a part in helping us get where we are today and together we can help provide support and research into treatments and ultimately cures for sight loss.



Mourne Mountain Challenge



Elaine Leinaweaver receives a generation donation from the Brenda Tompkins Dance Marathon

Upcoming Events

It's never too late to get involved. Get in touch with us today to join one of our exciting fundraising events or to arrange your own local event.

- October 17 – November 6: Everest Base Camp*
- November 5 – Glendalough Trail 15K
- November 18-27 – Cuba Trek*
- January 27 – February 5: Kilimanjaro Trek*
- February 3 – Sporting Luncheon

*Alternative dates available



Deborah McCann
Financial Controller

Statement of Financial Activities (Including Income And Expenditure Account) for the year ended 31st March 2011

| | 2011 € | 2010 € |
|---|------------------|------------------|
| Incoming Resources | | |
| Incoming Resources from Generated Funds | | |
| Voluntary Income | 308,565 | 380,737 |
| Activities for Generating Funds | 1,892,735 | 2,291,883 |
| Investment Income | 4,928 | 10,210 |
| Total Incoming Resources | <u>2,206,228</u> | <u>2,682,830</u> |
| Resources Expended | | |
| Costs of Generating Funds | 889,699 | 1,032,624 |
| Net Incoming Resources | <u>1,316,529</u> | <u>1,650,206</u> |
| Charitable Activities | 919,873 | 1,582,611 |
| Governance Costs | 14,156 | 24,272 |
| Total Resources Expended | <u>1,823,728</u> | <u>2,639,507</u> |
| Net Incoming Resources | 382,500 | 43,323 |
| Balance Forward at 1st April 2010 | (66,354) | (109,677) |
| Balance Forward at 31st March 2011 | <u>316,146</u> | <u>(66,354)</u> |

Statement of Total Recognised Gains and Losses

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 2011

| | 2011 € | 2010 € |
|--|------------------|------------------|
| Fixed Assets | | |
| Tangible Assets | 7,145 | 16,373 |
| Financial Assets | 458,092 | 278,092 |
| | <u>465,237</u> | <u>294,465</u> |
| Current Assets | | |
| Debtors | 83,968 | 127,422 |
| Cash at Bank | 351,755 | 497,900 |
| | <u>435,723</u> | <u>625,322</u> |
| Creditors: Amounts falling due within one year | <u>(584,814)</u> | <u>(762,011)</u> |
| Net Current Liabilities | <u>(149,091)</u> | <u>(136,689)</u> |
| Total Assets Less Current Liabilities | 316,146 | 157,776 |
| Creditors: Amounts falling due after more than one year | – | <u>(224,130)</u> |
| | <u>316,146</u> | <u>(66,354)</u> |
| Financed by: Accumulated Reserve/(Deficit) | <u>316,146</u> | <u>(66,354)</u> |

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,
Baldoye,
Dublin 13

The information above has been extracted from the financial statements of Fighting Blindness for the year ended 31st March, 2011. 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 Statement of Recommended Practice (SORP) for charities.



Back cover photos: Top Left: Des Cahill and Mick Galwey at the Sporting Luncheon; Bottom Left: Transylvania Trekkers
Right: Tony Ward and Paul Gorey run the Glendalough Trail **Front cover photos:** Left: Glendalough Trail 15K; Top Right: Researcher
in the lab; Bottom Right: Ann Cooke and Star at the Sporting Luncheon

Executive Office

Avril Daly, CEO

Accounts

Debbie McCann, Financial Controller

Fundraising

Elaine Leinaweaver, Head of Fundraising

Clodagh Ryan, Senior Fundraising Manager

Martina Madden, Fundraising Project Manager

Clare White, Direct Marketing Coordinator

Communications

Lauren Dare, Communications Executive

Research

Anna Moran, External Affairs Manager

Insight Counselling Centre

Mary Lavelle, Head of Counselling

Ann Cooke, Counselling Administrator

Board of Directors

Michael Griffith, Chairman

Tony Ward, Treasurer

Patricia Wallace, Secretary

Kevin Bowers

Pat Byrne

Colm Cronin

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Registered Charity No. CHY 6784
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