



**Fighting
Blindness**



Annual Report April 2008 - March 2009

**Fighting Blindness
Research. Counselling. Cures.**

About Fighting Blindness

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

Registered Charity Number
CHY 6784.
www.fightingblindness.ie

Highlights of 2008/2009



Fair City's Sorcha Furlong and Researcher Theresa Heffernan lead the way for the Fighting Blindness Mini Marathon team.



Michael Griffith, is congratulated by Mary Harney for his dedication to Fighting Blindness at his retirement celebration.

Rugby star Shane Byrne and wife Caroline at the annual Sporting Luncheon.



Our New Zealand trekkers fly the Irish flag on the opposite side of the globe.

Front cover: Fighting Blindness trekkers meet a group of Maasai children during a long hike through their grazing land in Tanzania.
Edited by Avril Daly and Lauren Dare. Design by Patricia O'Brien.

The Work of Fighting Blindness

Fighting Blindness is working to find treatments and cures 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 a unique 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 treatments and cures for blindness. It also provides a unique professional counselling service for people with visual impairments and their families.



(L-R) Michael Griffith, Steven Howarth and Prof Robin Ali at the Fighting Blindness AGM '08. Steven received revolutionary gene therapy by Prof Ali to dramatically improve his sight.

The year ending March 2008 was a challenging one for Fighting Blindness but we are delighted to report that our net income has been maintained with a small increase of 5% at €1,573,223. Our plans for significant growth were dampened by the current economic climate but we have refocused our fundraising efforts with new programs and initiatives. With a strong and able team at Fighting Blindness, and a committed supporter network we are optimistic about future growth.

Fighting Blindness invested an unprecedented €1,174,000 in research this year compared to €828,059 last year. The Fighting Blindness Vision Research Institute is up and running and our first project in adult stem cell research is underway. Professor Robin Ali - a world leader in his field, was appointed Associate Director of the Institute. We continued to fund research projects in universities and colleges covering five themes: gene therapies, stem cell therapies, novel drug therapies, population studies and artificial retina implants. All are making good progress. Our investment in Genable will help to considerably expedite the development of their gene therapy.

Substantial progress has been made in our Public Affairs and Communications activities with greater local and national media coverage. We launched a new website in January which is proving a very effective and accessible information resource and is attracting more and more activity.

Avril Daly our Head of Public Affairs, was elected to the board of the European Rare Disorders Organisation (EURORDIS) in May. EURORDIS is one of the most influential patients groups in the EU and is highly regarded by the EU Commission. Throughout the year we remained highly active both nationally and internationally in groups and organisations promoting research, policy development and implementation.

Our Insight Counselling Centre continues to strengthen with over 300 clients having availed of our services to date. Monthly support group meetings continue in Cork and Dublin and we continue to work hard to expand our service across Ireland.

Over the past year we have achieved significant advancements in all areas thanks to the tremendous efforts, dedication and hard work of all the staff and supporters of Fighting Blindness.

We would like to thank our members and thousands of supporters across the country for all their fundraising activities and personal contributions throughout the year towards Fighting Blindness. Their continued help and support is vital in advancing our search for cures and treatments for blindness.

The Fighting Blindness Team.



Michael Griffith, Chairman of Fighting Blindness.

Record €1,174,000 invested in Research in year to March last.

The past year has been hugely significant for Fighting Blindness with the commencement of our first project at the newly launched Fighting Blindness Vision Research Institute. This combined with the start of our three year investment in Genable Technologies Ltd. at Trinity College will have a major impact on the successful development of therapies for retinal degenerations. We continue to edge closer to therapies being available and are focused on making this happen. During the year we updated our research strategy with a clear implementation plan to inform our decisions. In total we invested €1,174,000 in research this year which was the biggest investment ever in a single year for Fighting Blindness.

This significant commitment to research has resulted in a deficit of €299,544 at year end creating an accumulated balance sheet deficit of €109,667. Our net income for the period grew to €1,573,223 which was a modest increase of 5%. This was disappointing based on our growth plans and reflected the difficult economic climate over the period. However we continue to maintain and build on our core support base and in spite of the extremely difficult environment, forecast a small growth over the coming year. As a result of this and a reducing commitment to research, as projects come to the end of their three year cycle, we are confident of eliminating our balance sheet deficit in the current financial year. We are glad to be able to report at mid way through the year, that we are on target to achieve this correction.

The Fighting Blindness Vision Research Institute (FBVRI), increased its research budget an astonishing five-fold in 2008-2009, and set a new level of endeavour in its search for treatments and cures for blindness. During this period we also learned about the exciting preliminary results of the very first gene therapy treatment for Leber's Congenital Amaurosis. This clinical trial is being conducted under the leadership of Prof. Robin Ali, University College London and Moorfield's Hospital.

In addition, 2008 has been a year in which Fighting Blindness consolidated and significantly advanced its research activities by expanding its research team at all levels. Having appointed a Head of Research (Prof. Michael Comer) in 2007, we recruited additional expertise in managing our research with the engagement of Dr. Patrick Corley. Patrick will perform the task of Assistant Scientific Director in charge of research administration at the FBVRI and our head office. We have also employed our first laboratory researcher Dr. Reaz Vawda to carry out stem cell studies in our own designated laboratories, based in the National Institute for Cellular Biotechnology (NICB) at Dublin City University.

Subsequently, as part of our strategy in creating critical mass and scientific quality we were proud to announce that Prof. Ali has accepted an invitation to join our organisation as an Associate Director of the Fighting Blindness Vision Research Institute. In the same vane, we are also very grateful to Prof. Jane Farrar, a Director at the Ocular Unit of the Smurfit Institute of Genetics, Trinity College Dublin who has also agreed to become an Associated Principal Investigator of the Vision Research Institute. Jane along with Prof. Peter Humphries and Prof. David McConnell, has been instrumental in establishing the cause of many heredity conditions in association with Fighting Blindness.

Research Strategy

During the year Fighting Blindness carried out a formal review of its research activities using the guiding principles of its Vision and Mission to set out goals for medium-and long-term achievements. Arising from this, key technology areas were identified for support and promotion of FBVRI well as the formal engagement with patients and the clinical community.

1. Research Projects

We continue to fund ten external projects under the general headings of genetics, cells and novel drug treatments whilst continuing our efforts to monitor and support retina implant technologies, population studies and clinical trials. These are all part of our Strategic Plan. Our strategic focus will remain directed towards degenerative retinal disorders whilst observing progress in the wider range of blinding conditions. We have decided in the short to medium term to concentrate our resources on the topics we believe are most promising, these are genetics and gene therapies and stem cells and cell therapies.

Gene therapy

- a) Leber's Congenital Amaurosis: Phase I involving three patients has been successfully concluded. Phase II gene replacement clinical trial for the RPE65 gene type of this condition has now commenced at Moorfield's hospital, London. Nine patients will be recruited in this next phase. Project FB07ALI
- b) Dominant RP, gene suppression and replacement therapy, is being advanced by the Genable campus company based at TCD. Project FB08GEN

Stem Cell Research

- a) Umbilical cord stem cells: Initial experiments have been carried out at the Fighting Blindness Vision Research Institute, to analyse the potential of these cells in retinal repair. Cells appear able to convert to nerve cells in laboratory, and when implanted appear to survive and grow.
Project FB08VAW

Novel Drug Therapy

- a) Selective opening of blood retinal barrier: Initial preclinical work at TCD appears successful, which holds the promise to allow new drugs to be used to treat neovascular AMD, without the need for monthly injections. Project FB09HUM

Population Research

- a) Macular pigment: Work on the distribution of macular pigment within the retina has concluded and been published. A new study has commenced to see if diet and weight loss affects macular pigment.
Project FB08BEA

Retina Implants

- a) Initial work on the design of novel electrodes at UCC has concluded. The new two-pole electrode research, which may allow greater contrast and finer resolution, is being written up for publication.
Project FB06ALD
- b) Internationally, the Argus II implant with a resolution of 60 electrodes is now in trial. The implant is suitable for extreme low vision and available for patients over 25 years of age. The implant allows basic orientation and street navigation.

2. Vision Research Institute

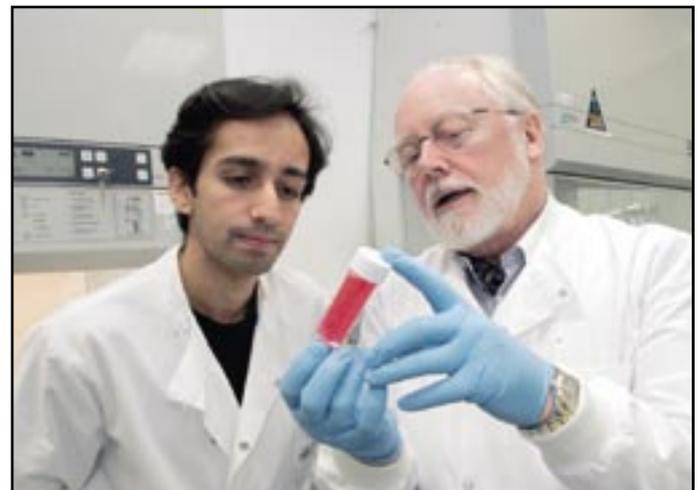
An extensive network of collaborations has been established spanning Ireland and the UK, including Trinity College Dublin, NUI Galway, Manchester Eye Bank, and Oxford University. Two scientific posters were published at research conferences in Ireland.

The Fighting Blindness Vision Research Institute has also carried out work for the European Vision Institute (EVI) and the EU, to gather information on databases of patients with retinal disorders across Europe. Formal linkages with Tübingen University in Germany and REMEDI in Galway are being advanced.

Outreach: In conjunction with the Insight Counselling centre, the Vision Research Institute has started a nationwide series of public lectures on vision research.

3. Campus Company

Genable a TCD Campus Company is being supported by Fighting Blindness in order to accelerate a potential therapy strategy. Work is in progress to develop a gene suppression and replacement protocol similar in principle to the work being carried out at Moorfields Hospital but slightly more complex.



Dr Reaz Vawada and Prof Mike Comer study stem cells in the Fighting Blindness Vision Research Institute.

Insight Counselling Centre Report

We are pleased to report the Insight Counselling Centre is now in its 7th year of operation offering professional counselling and psychotherapy to people with visual impairments as well as their family and friends. The concerns and stresses experienced by people with visual impairments do not differ hugely from those of the general population, but can be complicated by the condition. Concerns about spouses, partners, offspring and parents and their inter-relationships, coupled with worries about schooling, careers and future prospects, are among some of the issues that are explored by clients at Counselling Centre we also provide information, guidance, referrals and links to other related services through VISPA (Vision Impaired Service Providers Alliance).



Mary Lavelle and guide dog Star.

Our plans to extend the service nationwide have been somewhat curtailed due to the current economic climate. During the year, the Minister for Health and Children announced a reduction in the budget allocation to voluntary organisations providing services to people with disabilities. Notwithstanding the reduction, the financial support from the Dublin Mid-Leinster and Dublin North-East Areas of the Health Services Executive has enabled us to maintain the level of service we provide. We are very grateful for the ongoing financial support of the HSE, without which this service could not be provided. When the economic situation improves, we hope to implement our plans to provide a nationwide service. In the meantime, a telephone support service is available to those unable to travel or those seeking a more immediate response.

We continue 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 are very grateful to Ms. Dolores Leahy who gives so generously of her time each Thursday morning at the Eye Clinic in the Mater Hospital. Our monthly support group meetings in Dublin and Cork are also on-going. We wish to record our thanks to the Irish Guide Dogs for providing the venue for the Cork meetings.

On a sad note, we would like to acknowledge the passing of a dear friend and colleague Ann Byrne. Ann's contribution to Fighting Blindness and in particular her association with the peer counselling service was invaluable. Her determination and conviction were hugely instrumental in securing the initial funding to establish a professional counselling service. Ann's death has left a great sadness and she will be deeply missed by all of us whose lives she touched so warmly.

We would like to thank our corporate sponsors for their continuing support for the Insight Counselling Centre and all those who take part and support Fighting Blindness events. Your contribution is essential to the development of this vital service.

If you would like any further information or if we can help in any way, please do not hesitate to contact us at (01) 674 6496 or email insight@fightingblindness.ie

Mary Lavelle
Senior Counselling Psychologist



Avril Daly, Head of Public Affairs.

New Initiatives and an Established Support Network Lead to a High Profile Year for Fighting Blindness

A number of individuals, agencies and companies supported the communications team at Fighting Blindness this year by donating their time and expertise to help spread our message.

We are very grateful to the TV team at CityJet in Dublin who produced a four-minute film highlighting the work of Fighting Blindness. The media company Clear Blue Water and Pembroke Communications donated their advice and support to ensure that we maximised on all media opportunities. Throughout the year, we received support from Irish newspapers and magazines that carried our adverts free of charge. We were also honoured to be selected by the Press Photographers Association Ireland as the beneficiaries of the highly coveted Beyond the Moment photo book. All of this support is invaluable to our organisation and we are extremely grateful to all who made this year our most high profile to date.

To ensure that we continue to provide accessible information, we undertook a rebranding of our communications materials. With the support of the Health Service Staff Credit Union (HSSCU), Fighting Blindness launched a new website in January 09, now receiving over 13,000 hits a month. We revamped our Visionaries Newsletter, circulated to 6,000 readers twice a year in spring and autumn, and introduced an Ezine distributed to our list of 5,000 active online supporters every six weeks.

This year also saw more of our members sharing personal experiences with us and the media. This is never an easy thing to do and so we would like to extend our thanks to all of you who told your stories to the national and local press, as well as on radio and television.

As an organisation representing people with rare eye disorders, it is vital that we work with national and international organisations, scientists, policy makers and industry representatives to make our voice stronger. We are represented on the board of the European Platform for Patients' Organisations, Science and Industry (EPPOSI) and the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI). These groups act as a platform to promote cooperation between stakeholders in research development in order to inform European and Irish policy on these important health issues.

Through our work with the Irish national alliance for people with rare disorders, the Genetic and Rare Disorders Organisation (GRDO), Fighting Blindness was elected to the board of the European Rare Disorders Organisation (EURORDIS). On February 28, 2009, we participated in the international 'Rare Day for Rare Disorders' to advocate for better access to diagnosis and treatments, and to call on the Irish Government to implement a national plan for rare disorders.



Head of Public Affairs, Avril Daly, with Sen Deirdre DeBurca and Lord Mayor of Dublin Cllr Eibhlin Byrne at the launch of Rare Diseases Day 09.

On World Sight Day (October 9, 2008), the Vision Impaired Service Providers Alliance (VISPA) launched the report 'Eyes on the Future', highlighting the significant growth in the numbers of people affected by visual impairments in Ireland and the urgent need for an increase in services to facilitate our aging population. Fighting Blindness, the National Council for the Blind, Irish Guide Dogs for the Blind and St Joseph's Centre for the Visually Impaired established VISPA in 2008 to be a cohesive voice advocating for increased understanding and awareness of needs and services for people who are blind or vision impaired.

Fighting Blindness plays a significant role in the promotion of public awareness of degenerative sight loss and in the provision of information to all interested parties. We continue to work internationally with organisations such as Retina International and the AMD Alliance, which enables us to deliver up-to-the-minute information on global developments in research.

Education is vital to the discovery of treatments and cures for blindness in the shortest possible time frame. It is essential that the broad network of researchers, scientists and clinicians, whether they are funded by Fighting Blindness or not, are kept up to date with developments in ophthalmic research both domestically and internationally.

Over the past ten years Fighting Blindness has attracted the world's leaders in ophthalmic research, particularly retinal research and stem cell therapy, to speak to Irish researchers at the annual All Ireland Retinal Research Network (AIRRN) and Irish Network of Neural Stem Cell Investigators Network (INNSI) conferences. These networks were established to facilitate optimum cooperation and collaboration between researchers and clinicians, thereby further accelerating the search for treatments and cures for blindness.

I would like to thank our members and friends for your invaluable support and assistance throughout this year. We very much look forward to working with you in 2009-2010.

Avril Daly
Head of Public Affairs



Fighting Blindness trekkers succeed in making it to Everest Base Camp.



TV3 presenter Lorraine Keane helps launch Light for Sight, our annual fundraising and awareness campaign.

Our gross income of €2,467,225 and net contribution of €1,573,223 consolidated our income on the previous year with a 5% increase.

The National Raffle was again the main income generator for the year. Over 17,000 people participated and raised €720,359. In addition our Private Members Draw continues to grow to with over 5,000 members generating €442,626 at year end.

We completed successful overseas treks to New Zealand, Tanzania and Nepal and also a weekend challenge in Wicklow. As a result of the tremendous fundraising efforts from our loyal band of trekkers and their supporters we raised over €220,000. We look forward to their continued support as we take on Everest Base Camp, Peru and Transylvania in the coming year.

Our Fighting Blindness Sporting Lunch at the Shelbourne Hotel, Dublin in February was a great success and raised over €35,000. Thank you to all those who attended for their generosity and to the committee for all their hard work.

A particular thank you to the Press Photographers Association of Ireland for making Fighting Blindness the beneficiary of their book "Beyond the Moment" and to the Health Services Staffs Credit Union for their sponsorship of our website.

The fundraising team would like to thank all our supporters who continued to give of their time and energy to raise funds for us. This included organising church gate collections, taking part in treks and challenges, running marathons and mini marathons, skydiving and organising or attending hundreds of events throughout the year.

Thank You

Upcoming Events in 2010



FM104's Stephen Daly took a leap for Fighting Blindness. Will you? Sign up for an Active Challenge today!



Inca Trail, Peru Trek. March 2010.

February – Sporting Luncheon

Book your table for our second annual Sporting Luncheon featuring legends from the world of rugby and racing. Last year's luncheon was very popular and a great way to bring some style to the Six Nations season.

February – Skydive

Get some height to save sight! We're having a big skydive weekend to raise money for our research. Wouldn't you like to feel the wind through your hair as you free-fall over Co. Offaly?

March – Peru Trek

Adventurers are welcome to join us as we trek the legendary Inca trail from Cusco to Machu Picchu.

May – Transylvania Trek

Trekkers with moderate fitness can spend five days with us in a hidden corner of Europe full of enchantment and mystery.

June – Night Walk

Inaugural 20 mile walk through Dublin City Centre, in association with The Diabetes Foundation Ireland.

September – Mourne Challenge

Grab your team and head up North to test your limits in this challenging adventure.

October – National Awareness & Fundraising Campaign

Join us as we spread awareness of our work to fight blindness. Host your own event or join the bucket brigade in major shopping centres across the country.

October – Fighting Blindness AGM

Autumn – Everest Base Camp Expedition

Take part in the adventure of a lifetime in our annual trek to the top of the world!

For more details about these events:

Call: +353 1 709 3050

Email: fundraising@fightingblindness.ie

Visit: www.fightingblindness.ie

Board of Directors

Patricia Burke
Pat Byrne
Stephen Farrelly
Michael Griffith
Frank Kelly
Colette McNamee
Dave Waldron - Chairman
Tony Ward

Staff

CEO's Office

Patrick Quinn, Chief Executive; Anna Moran, HR & Administration Manager

Research

Prof Mike Comer, Head of Research; Dr Patrick Corley, Research Manager; Dr Reaz Vawda, Research Scientist; 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, Senior Fundraising Manager; Elaine Leinaweaver, Senior Fundraising Manager; Sue Ryan, Events Coordinator; Barbara Cahill, Community Events Coordinator; Emma Horgan, Corporate Development

Accounts

Deborah McCann, Financial Controller; Padma devi Ramalingam, Senior Bookkeeper; Margaret Glover, Financial Assistant

Insight Counselling Centre

Mary Lavelle, Head of Counselling; 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 MJ Kennedy & Co
Parochial House
14 Main Street
Baldoye
Dublin 13

FIGHTING BLINDNESS
(COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE CAPITAL)

STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31st MARCH 2009

	<u>2009</u>	<u>2008</u>
	—	—
<u>Incoming Resources</u>		
Incoming Resources from Generated Funds		
Voluntary Income	420,297	384,338
Activities for Generating Funds	2,016,403	2,099,189
Investment Income	30,525	17,406
<u>Total Incoming Resources</u>	<u>2,467,225</u>	<u>2,500,933</u>
<u>Resources Expended</u>		
Costs of Generating Funds	894,002	1,002,389
	<u> </u>	<u> </u>
<u>Net Incoming Resources</u>	<u>1,573,223</u>	<u>1,498,544</u>
Charitable Activities	1,899,269	1,597,050
Governance Costs	11,589	10,703
	<u> </u>	<u> </u>
<u>Total Resources Expended</u>	<u>2,804,860</u>	<u>2,610,142</u>
<u>Net Outgoing Resources</u>	<u>(337,635)</u>	<u>(109,209)</u>
Reinstatement of Financial Asset Investments	38,091	-
	<u> </u>	<u> </u>
<u>Net Movement in Funds</u>	<u>(299,544)</u>	<u>(109,209)</u>
Balance Forward at 1st April 2008	189,867	299,076
	<u> </u>	<u> </u>
Balance Forward at 31st March 2009	<u>(109,677)</u>	<u>189,867</u>
	<u> </u>	<u> </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.

FIGHTING BLINDNESS
(COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE CAPITAL)

BALANCE SHEET AS AT 31st MARCH 2009

	<u>2009</u>	<u>2008</u>
	—	—
<u>Fixed Assets</u>		
Tangible Assets	27,840	24,995
Financial Assets	238,092	1
	<u>265,932</u>	<u>24,996</u>
<u>Current Assets</u>		
Stocks	1,000	2,996
Debtors	125,687	114,273
Cash at Bank	681,752	1,129,217
	<u>808,439</u>	<u>1,246,486</u>
<u>Creditors:</u> Amounts falling due within one year	<u>(1,184,048)</u>	<u>(1,081,615)</u>
<u>Net Current (Liabilities)/Assets</u>	<u>(375,609)</u>	<u>164,871</u>
<u>Total Assets Less Current Liabilities</u>	<u>(109,677)</u>	<u>189,867</u>
<u>Financed by:-</u>		
Accumulated (Deficit)/Reserves	<u>(109,677)</u>	<u>189,867</u>



Fighting Blindness

Fighting Blindness

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Insight Counselling Centre

4 South Great George's Street, Dublin 2.

Tel: 01 674 6496 Fax: 01 674 6497

Email: insight@fightingblindness.ie

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.