

Fighting Blindness

Fundraising for a Rare Disease Patient Group

EURORDIS Membership Meeting 2012

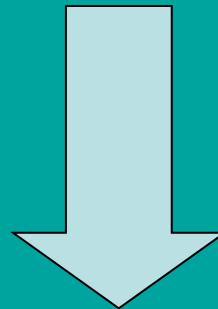
23 May 2012

Avril Daly – Fighting Blindness

Current Situation

Over 200,000 children and adults in Ireland

Over 40 million worldwide



**Genetic, degenerative and
age-related eye conditions**



**Fighting
Blindness**

What Fighting Blindness is all about

- **CURE**



- **SUPPORT**



- **EMPOWER**



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.



Fundraising was the key



Fighting
Blindness

Fighting Blindness Beginnings

1. Case for Support

- 1983 TCD research into RP to find genes responsible

2. Fundraising Goal

- IR£100,000 over three years

3. Membership & Volunteer Base

- Most interested and committed supporters

4. Fundraising Method: Car Draw

- Popular in local communities
- Raised IR£115,000

5. Develop relationships and networks

- Foundation Fighting Blindness
- \$500,000

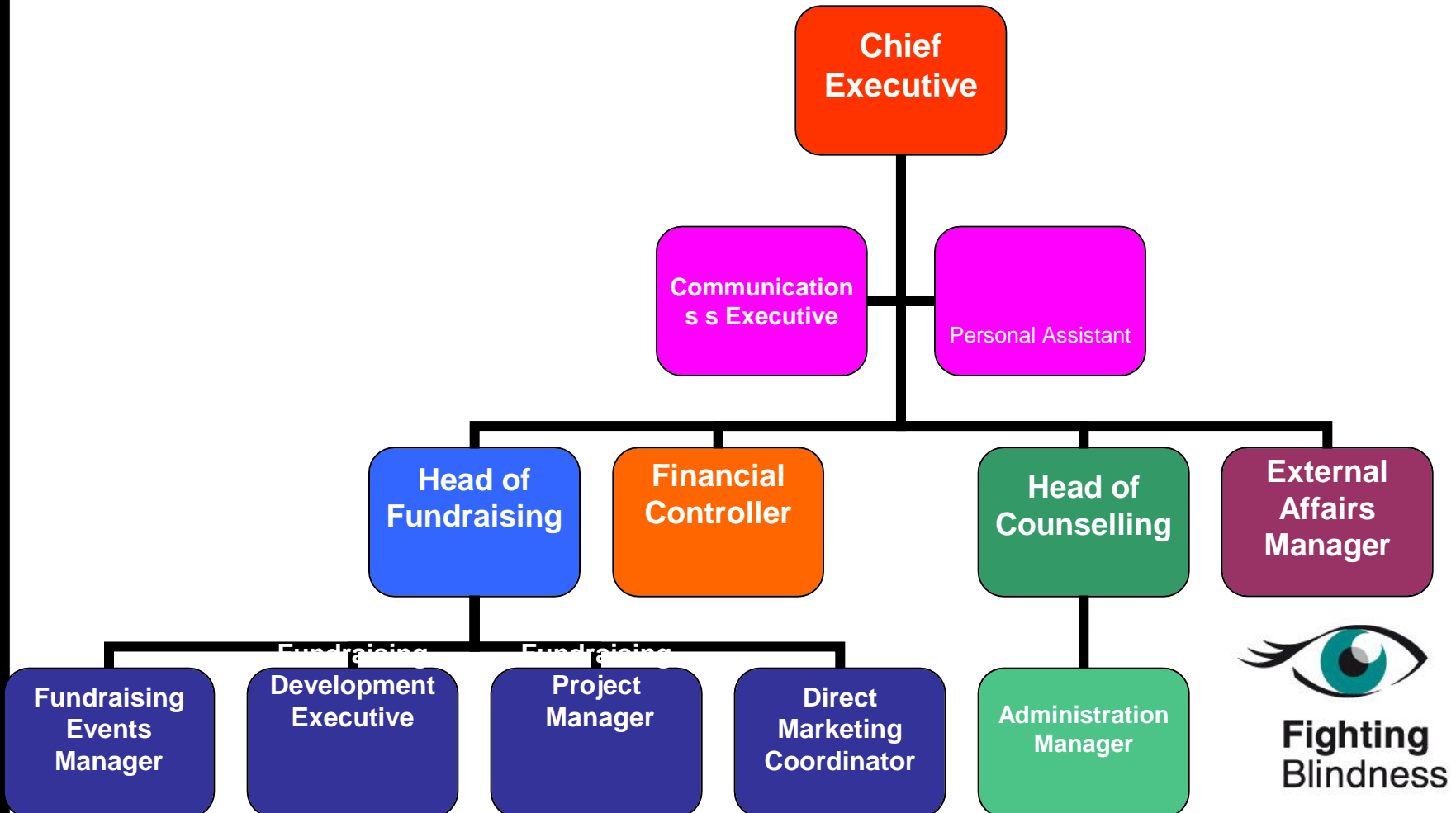


**Fighting
Blindness**

Fundraising Today

- **Medical Research is expensive and lengthy. Fundraising for Fighting Blindness is the cornerstone on which Cures, Support and Empowerment are financed.**
- **FB needs to raise an annual target of 2.5 million Euros to continue funding projects in research, counselling & advocacy.**

Staff Structure at Fighting Blindness



5 staff in Fundraising department

- **Head of Fundraising** Overall responsibility to raise 2.5million Euro per annum
- **Community Development Manager** – develop fundraising initiatives in local communities and groups
- **Events Manager** – Fundraising through events such as adventure activities, cycles, treks, marathons
- **Special Project Manager** – Target 3000
- **Direct Marketing Coordinator** – Managers third party fundraisers, national raffle, private members draw and door to door, direct debit



Signature Events

- Head of Fundraising works with CEO in the organisation, sale and execution of high level events such as gala dinners and our Sporting Luncheon
- This event is attended by high net worth members and supporters and is hosted on the day before the commencement of the Six National Rugby campaign and the weekend of the Hennessy Cognac Gold Cup



Shane's little helpers bid to tackle blindness

JURORS Donk night star Shane Byrne yesterday teamed up with Clare O'Brien, US, Clara Daly (4) and Violet Cullen (2) to raise funds for Fighting Blindness.

The ex-Leinster hooker is a patron of the charity and will be giving a personal training session to a lucky bidder in next month's sporting luncheon. A signed Ireland World Cup jersey will also be among the items going under the hammer.

Mr Byrne and former Leinster scrum-half Bernard Jackman will join former Ireland fly-half Brian O'Leary and Dan O'Keefe at the Westin Hotel on Friday February 3 for the fourth annual charity lunch.

The event takes place ahead of Ireland's opening game in the Six Nations Championship against Wales in the Aviva Stadium on February 5.

The charity is aiming to raise €10,000 on the day to fund research into the treatment and care of blindness. More than 200,000 people

have suffer from blindness and vision loss due to conditions such as age-related macular degeneration, diabetic retinopathy and cataracts. These individuals can contact the charity on 01 709 2020.

ALLISON BRAY



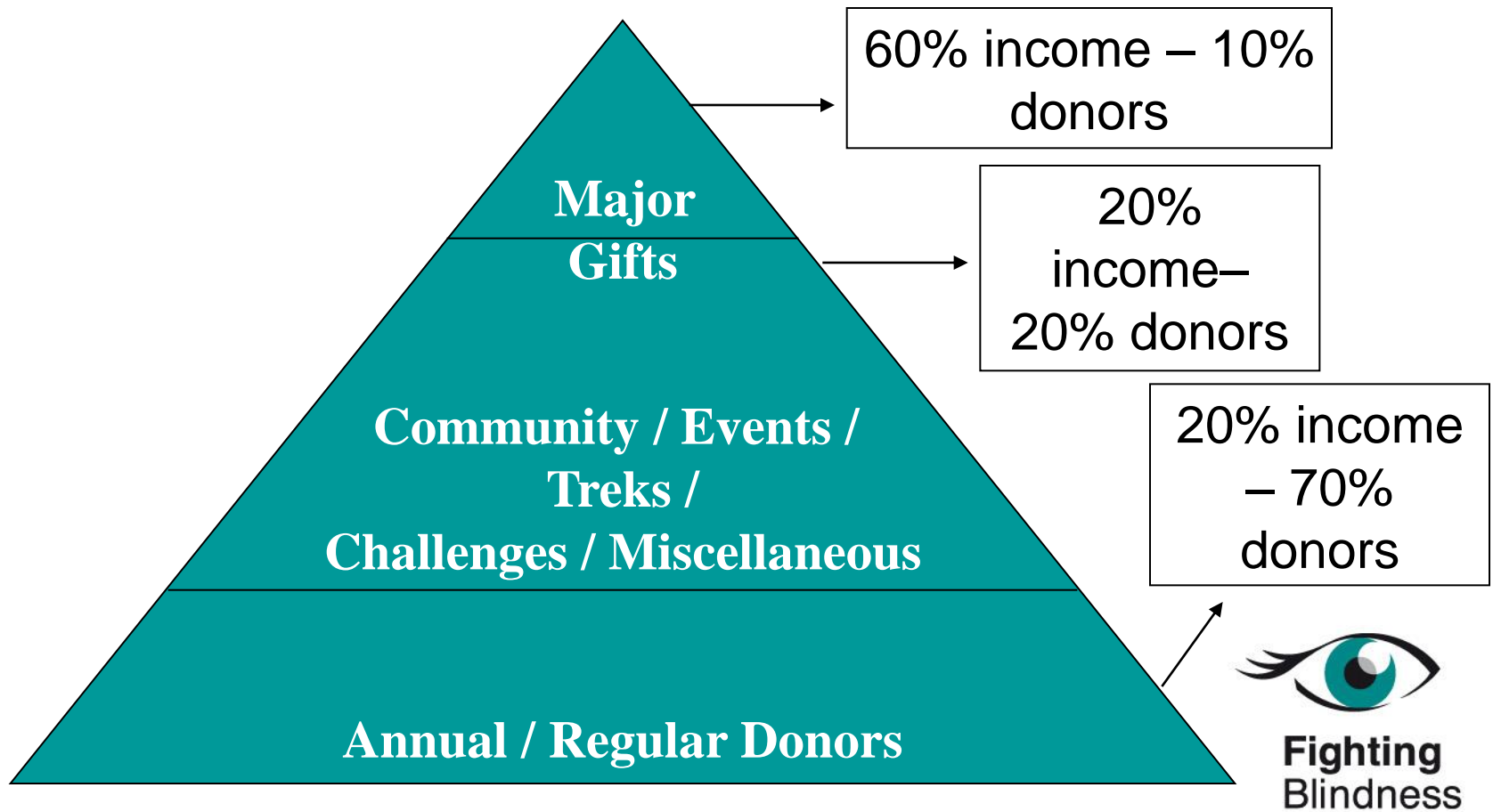
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Sponsorship of Events

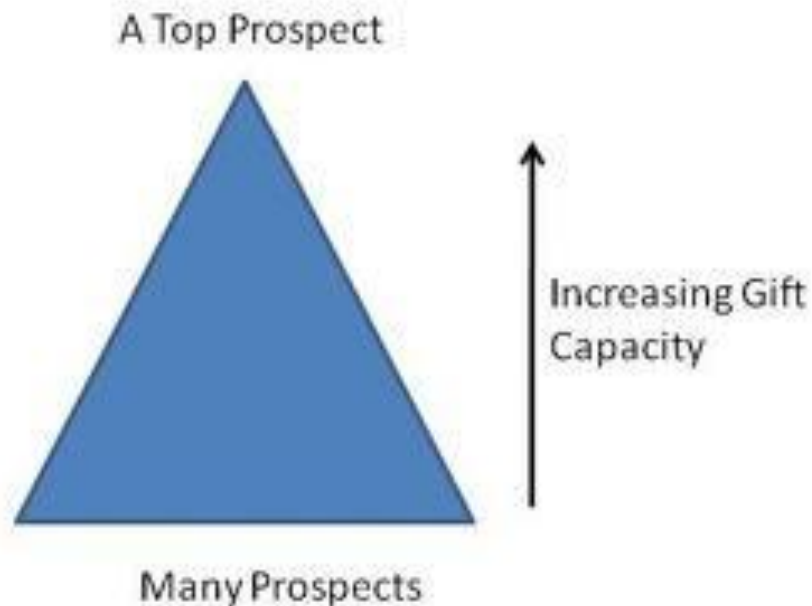
- **The Head of Fundraising and External Affairs Manager works with the CEO in attracting sponsorship for events that fulfil our strategy for example our Retina Conference every November**



Fundraising Pyramid



Increasing Gift Capacity



Many leads are required to reach the few that can make larger gifts and can leave legacy donations to your organisation

Diversified Income (1)

1. Direct Marketing

- Regular donor support (direct debits)
- Raffles & draws
- Often lead to future legacy donors

2. Community / Volunteers

- Members
- Local events & activities
- Schools
- Local Clubs



Diversified Income (2)



3. Events

- Treks / Challenges
- Signature Events
- Information evenings

4. Corporate Support

- International foundations
- Charity of the Year
- Sponsorship
- Employee fundraising

New Code of Practice

Statement of Guiding Principles for Fundraising

1. Core Principles

- **Respecting the rights, dignity & privacy of supporters, clients & beneficiaries**
- **Answering reasonable questions about fundraising activity & fundraising costs honestly**
- **Making information about our purpose, activities & governance available to the public**

2. Commitment to Donors

- **Donor's Charter – commitment regarding:**
 - **cause for which charity is fundraising**
 - **use of donations**
 - **status & authority of those soliciting donations**
- **Complaints & Feedback Procedure**

3. High Standards of Fundraising Practice

- **Information & training provided to all fundraisers to ensure commitment to highest standards of good practice**
- **Fundraising activities always respectful, honest, open and legal**
- **Policy in place regarding the management of volunteer fundraisers**

4. Financially Accountable

- **Publish annual report and statement of annual accounts**
- **Appropriate internal financial and management controls**
- **All donations to be recorded and records to comply with data protection legislation**

5. Board & Senior Management Responsibility

- **Ensure compliance with the Statement of Guiding Principles for Fundraising**
- **Identify any risks that may arise**
- **Ensure appropriate mechanisms are in place to manage and deal with those risks**

Our Vision

- **At Fighting Blindness we believe we are close to the goal we set for ourselves 30 years ago – to find a cure for blindness**
- **Medical research is expensive and lengthy – the only way we can achieve this goal is through fundraising**
- **We need long term funding and investment in the innovative research happening in laboratories across Ireland**

Where to find us

Follow us on Twitter: www.twitter.com/fightingblindes
Be a Fan: www.facebook.com/fighting.blindness.ireland

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Thank You



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