

# **Fundraising: Resourcing Patient Organisations for a strong Patient Movement**

## **COLLABORATION – PARTNERSHIPS in EU projects**

**5th EFP Regional Advocacy Seminar**

**Lisbon 25-26 October 2012**

**Carmen Netzel**



European Consortium for the Early Treatment of Diabetic Retinopathy



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**EUROCONDOR****European Consortium for the Early Treatment of Diabetic Retinopathy**

Coordinator: Rafael SIMO CANONGE

Project Number: 278040

EC contribution: € 5,998,762,00

Project website: <http://eurocondor.eu/>

Diabetic retinopathy (DR), the leading cause of blindness among working-age individuals in developed countries has been classically considered to be a microcirculatory disease of the retina. However, there is growing evidence to suggest that retinal neurodegeneration is an early event in the pathogenesis of DR. For this reason, it is reasonable to hypothesize that therapeutic strategies based on neuroprotection will be effective not only in preventing or arresting retinal neurodegeneration but also in preventing the development and progression of the early stages of DR (ie. microaneurysms and/or retinal thickness).

EUROCONDOR (European Consortium for the Early Treatment of Diabetic Retinopathy) is a solid and well balanced consortium (ophthalmologists, endocrinologists, basic researchers) which has been created in order to implement the first clinical trial using eye drops for treatment of the early stages of DR. The participants are top leaders in their field and central readings will be performed by the Coordinating Centre of the European Vision Institute Clinical Research Network (EVICR.Net).



European Consortium for the Early Treatment of Diabetic Retinopathy

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The main objectives of the project are the following:

#### Primary objective:

To assess whether the selected neuroprotective drugs (brimonidine and somatostatin) administered topically are able to prevent or arrest neurodegeneration, as well as the development and progression of the early stages of DR.

#### Secondary objectives:

1. To determine the prevalence of functional abnormalities related to neurodegeneration in those patients without or with minimal microvascular damage under ophthalmoscopic examination.
2. To compare the without: sense [Desactiva](#) gs.
3. To evaluate the local and systemic adverse effects of the selected drugs.
4. To identify those patients most prone to progressive worsening (characterization of phenotypes and circulating biomarkers).
5. To determine the molecular mechanisms by which the selected drugs exert their beneficial effects.



Is a partner in EUROCONDOR consortium; they participate in the Dissemination workpackage:

IDFE will participate in WP4 (Dissemination) and will be member of the Ethics Committee and member of the Dissemination Board. IDF-Europe will act a bridge between EUROCONDOR and the different associations of diabetic patients throughout Europe. Moreover, IDF- Europe will also use the following tools and events in order to disseminate the findings of the project:

- IDF Europe intranet and annual General Assembly
- Diabetes related congresses (e.g. European Association for the study of Diabetes, World Diabetes Congress, etc)
- European Diabetes Coalition
- World Diabetes Day (14 November)
- Via health professional organizations (Primary Care Diabetes Europe, Federation of European Nurses in Diabetes, Federation of Dieticians)

The International Diabetes Federation (IDF) is an umbrella organization of over 200 national diabetes associations in over 160 countries. It represents the interests of the growing number of people with diabetes and those at risk. The Federation has been leading the global diabetes community since 1950.

IDF's mission is to promote diabetes care, prevention and a cure worldwide.



Association for Innovation and Biomedical Research on Light and Image

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## CEC // Centre for Clinical Trials



The Clinical Trial Centre (CEC) performs randomized clinical trials with special emphasis on ophthalmology and neurology.

CEC has dedicated facilities and the most modern ophthalmological equipment. Its permanent staff includes two medical doctors, one pharmacist, three technicians for diagnostic procedures, six study coordinators and two administrative secretaries. 20 other medical doctors, three technicians for diagnostic procedures, one

### Areas of expertise

#### Retina:

- Identification of phenotypes and biomarkers of retinal disease progression
- Testing new methods of early diagnosis of macular edema and retinal vascular disease
- Characterisation of responders and non-responders to new available therapies of retinal disease
- Characterization of phenotypes of diabetic retinopathy





# Institut de Recerca Hospital Universitari Vall d'Hebron

*Institut d'Investigació Sanitària de l'Institut de Salut Carlos III (ISCIII)*



## CONTACT

Fátima Núñez

[fatima.nunez@vhir.org](mailto:fatima.nunez@vhir.org)

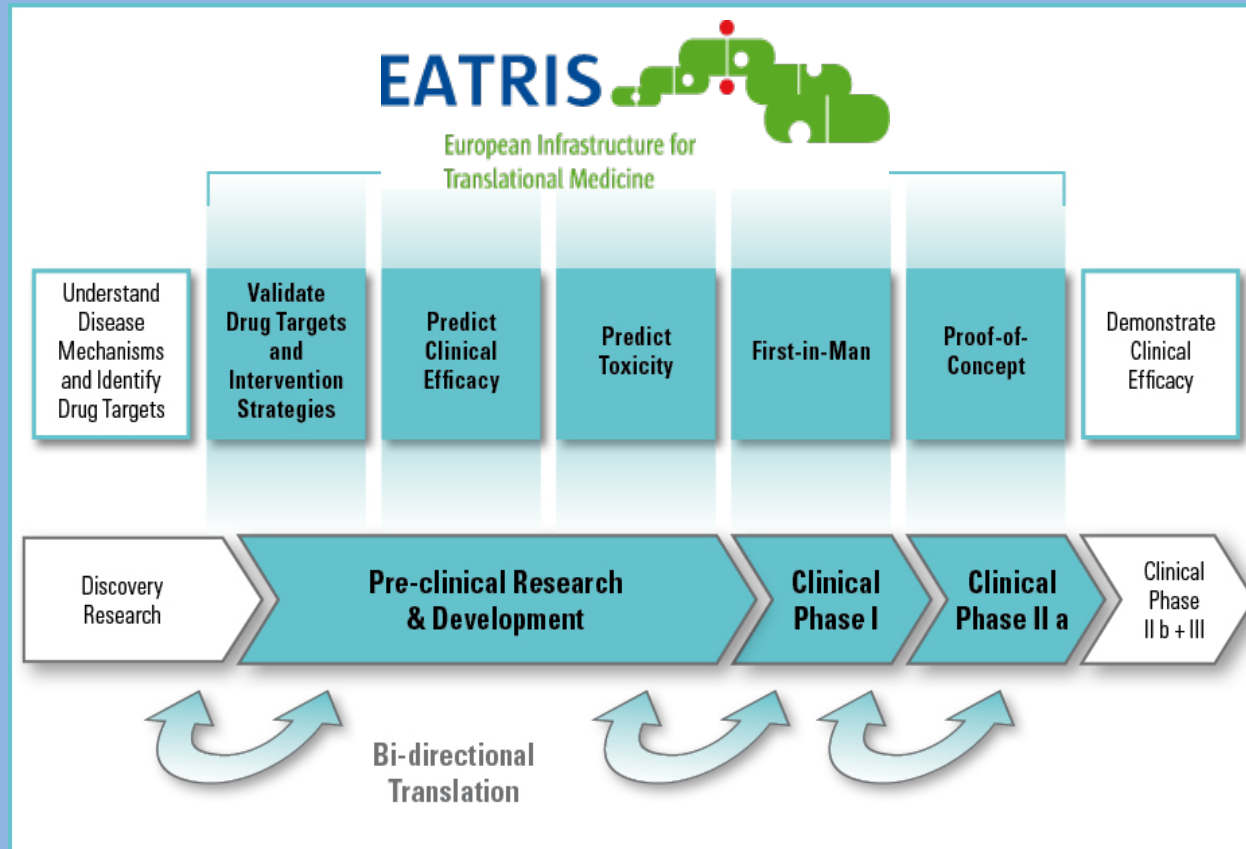
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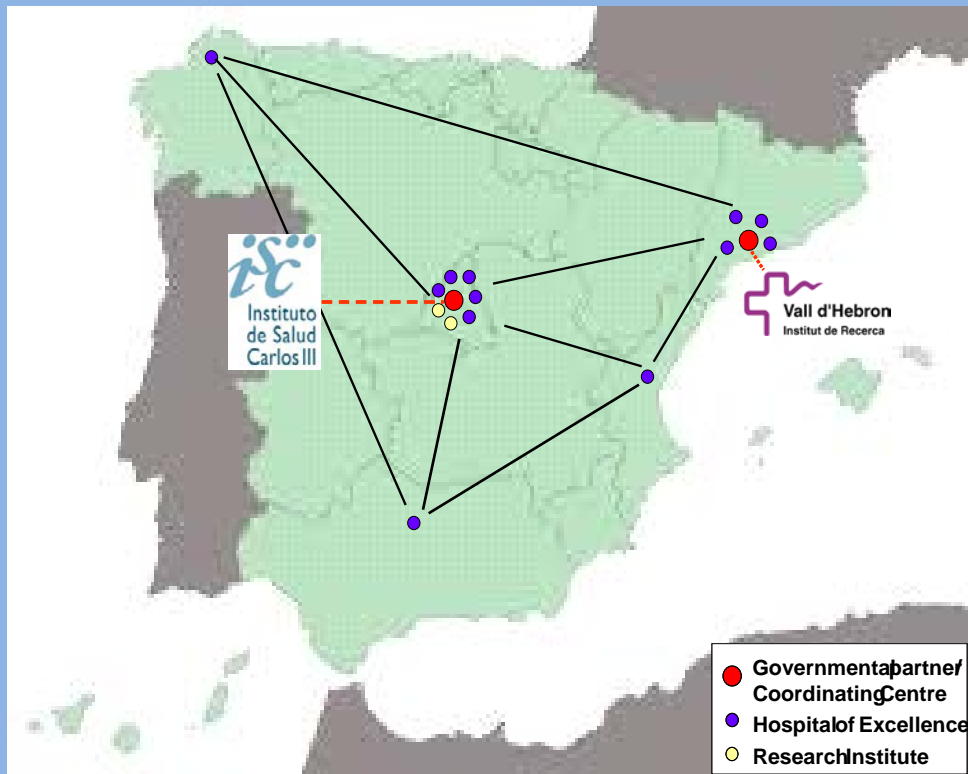
October 2012

# EATRIS | WHAT AND WHY?

**EATRIS (the European InfraStructure for Translational Medicine) *transforms and accelerates* scientific discoveries into innovative and high impact medicines, diagnostics and medical devices.**



**EATRIS.[ES] represents the biggest EATRIS contribution...**



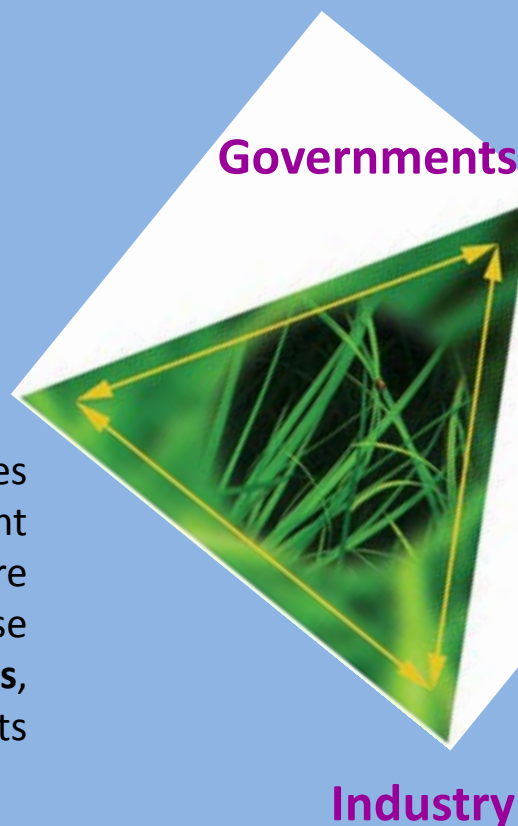
- **COORDINATOR:** Inst. de Recerca Vall d'Hebron
- Inst. d'Invest. Biomèdiques August Pi i Sunyer
- Inst. d'Investigació Germans Trias i Pujol
- Inst. d'Investigació Biomèdica de Bellvitge
- Inst. de Recerca Hosp. Santa Creu i Sant Pau
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- Centro Nacional de Invest. Oncológicas
- Centro Nacional de Invest. Cardiovasculares



....within a European collaborative consortia of academic, patients, industrial and governmental partners...

## Academia and Patients

- Fundamental discoveries
- Excellent pre-clinical development
- Excellent research infrastructure
  - Translational expertise
- Access to **patient groups**, clinical experts



- Access to regulatory agencies
- Access to reimbursement instances
- Resources to support critical infrastructure
- Coordination & dialogue among EU countries
- Long-term vision for improved, cost-effective patient care

- Excellence in clinical development
- Understanding of patient needs
- Resources to enter risky clinical phase
- Production
- Global reach in marketing & sales

# EATRIS | HOW?

...with an organizational matrix that combines 'horizontal', 'vertical' and 'diagonal' expertise on 6 diseases and 5 products of the utmost clinical relevance.



# THANK YOU!

Carmen Netzel  
Head Development Office  
Vall d'Hebron Research Institute Foundation  
[www.vhir.org](http://www.vhir.org)  
carmen.netzel@vhir.org