

AS A RESULT OF MORE THAN 10 YEARS OF WORK, ENERCA OFFERS A SOLID PLATFORM FOR DEVELOPING MULTIDISCIPLINARY INITIATIVES TO TACKLE RARE ANAEMIAS.



European Network for Rare and Congenital Anaemias



Co-funded by the Health Programme of the European Union



Institut d'Investigacions Biomèdiques August Pi i Sunyer



Hospital Universitari



UNIVERSITAT DE BARCELONA



**Contact info:**

**IDIBAPS - Hospital Clínic de Barcelona**

Villarroel, 170 / Block 9, Floor 0  
08036 Barcelona (Spain)

Tel. +34 93 451 59 50

[enerca@enerca.org](mailto:enerca@enerca.org) / [www.enerca.org](http://www.enerca.org)



European e-health services for a better  
management of rare anaemias

**e-ENERCA**

**ENERCA** (European Network for Rare and Congenital Anaemias) is a European Commission co-funded project launched in 2002 with the purpose of **offering improved public health services in rare anaemias to both professional medical practitioners and patients, independently of their country of practice or origin.**

## Creating a European Reference Network of Centres of Expertise on Rare Anaemias



### ENERCA I (2002-2004)

- Network of experts
- Clear and concise contents
- Diagnostic protocol

### ENERCA II (2005-2008)

- Network consolidation
- Haemoglobinopathies database
- Dissemination

### ENERCA III (2009-2013)

- Guidelines
- Social awareness
- White Book

### e-ENERCA (2013...)



The strategic importance of e-ENERCA lies in promoting the participation of European health professionals, patients, health authorities and other stakeholders in the improvement of health services **geared towards better performance in tackling rare anaemias**. This will be achieved through the design, validation and implementation of new Information and Communication Technologies (ICTs).

e-ENERCA brings together the efforts of **26 partners**, all acknowledged experts in their respective field of rare anaemias, **from 11 European countries**. The majority of them have been working together within ENERCA since 2002.



### Coordinator

Institut d'Investigacions Biomèdiques August Pi i Sunyer - Hospital Clínic de Barcelona (Spain)

Head of Project: Joan-Lluís Vives Corrons

Project Manager: Maria del Mar Mañú

Project Assistant: Laura Olaya Costa



### Associated partners

Centre Hospitalier Universitaire de Montpellier (France) · Patricia Aguilar Martínez

Cyprus Foundation for Muscular Dystrophy Research (Cyprus) · Marina Kleanthous

European School of Haematology (France) · Didi Jasmin

Foundation IRCCS Cà Granda Ospedale Maggiore Policlinico Milan (Italy) · Paola Bianchi

Hôpital Erasme - Université Libre de Bruxelles (Belgium) · Béatrice Gulbis

King's College London School of Medicine (United Kingdom) · Swee Lay Thein

Thalassaemia International Federation (Cyprus) · Androulla Eleftheriou and Michael Angastiniotis

Universidad del País Vasco / Euskal Herriko Unibertsitatea (Spain) · Carlos Romeo and Pilar Nicolás

University Medical Center Utrecht (Netherlands) · Richard van Wijk

University of Cyprus (Cyprus) · Christos N. Schizas

West Hertfordshire Hospitals NHS Trust (United Kingdom) · Barbara de la Salle



### Collaborating partners

Aristotelian University of Thessaloniki (Greece) · Panayiotis D. Bamidis

Centre Hospitalier Universitaire de Toulouse e- HEMATImage (France) · Joel Corberand

Centro di Ricerca per l'Ingegneria Genetica (Italy) · Achille Iolascon

Centro Hospitalar Coimbra (Portugal) · Leticia Ribeiro

Centro Nazionale Malattie Rare and Europlan Project (Italy) · Domenica Taruscio

Clinic of Pediatric Hematology and Oncology, St. Marina University Hospital of Varna (Bulgaria) · Valeriya Kaleva

Cyprus Thalassaemia Centre (Cyprus) · Soteroula Christou

Hôpital Robert Debré (France) · Lydie da Costa

Institute of Predictive and Personalized Medicine of Cancer (Spain) · Mayka Sánchez

Università Degli Studi de Milano (Italy) · Andrea Mosca - Domenica Cappellini

Università Vita-Salute San Raffaele (Italy) · Clara Camaschella

University of Athens, Biomedical Research Foundation (Greece) · Dimitris Loukopoulos

University of Ulm (Germany) · Hermann Heimpel

## ENERCA WHITE BOOK: TOWARDS A EUROPEAN NETWORK OF CENTRES OF EXPERTISE

The recognition of centres of expertise for rare anaemias will be promoted by establishing links between the European Commission and national organisations of member states responsible for specific plans for rare diseases, European and national scientific communities, health care authorities and patients' associations.

The ENERCA White Book recommendations will provide the practical material and the specific methodology requirements necessary to advance towards the consolidation of a European Reference Network of Centres of Expertise in Rare Anaemias, which is a crucial step for improving the clinical management of rare diseases that cause anaemia.

**It is estimated that 30% of rare anaemias are undiagnosed or misdiagnosed**

Conceived as a working tool addressing a wide variety of stakeholders, the White Book is a compendium of recommendations to be met by Centres of Expertise in Rare Anaemias and recommendations for establishing national networks for rare anaemias.

The White Book features three main issues:

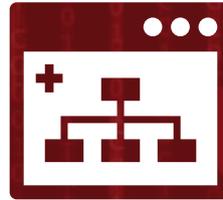
- The ethical and legal perspective, to improve and guarantee respect for patients' rights and interests.
- A technical and professional description of procedures for implementing an updated diagnosis, monitoring and treatment of rare anaemias.
- A detailed report of patients' expectations, based on widespread surveys conducted in collaboration with patients' associations.

**About 90 rare anaemias have been described, most of them hereditary**



e-ENERCA will incorporate innovative e-health Information and Communication Technologies (ICTs) to create a **pan-European interoperable platform** for teleexpertise/telediagnosis, electronic registry/epidemiological surveillance and e-learning/continuing medical education in rare anaemias. This will

create a collaborative environment for disseminating knowledge and awareness on rare anaemias, with a view to facilitating best practice improvement and validation for the best diagnosis and clinical management of patients with rare anaemias in Europe, wherever they are located.



[www.enerca.eu](http://www.enerca.eu)

## e-REGISTRY

FOR EPIDEMIOLOGICAL SURVEILLANCE

An inventory of centres of expertise and epidemiological figures will provide ENERCA with comparable data from all around Europe. The electronic database and a front-end online tool will serve as a registry and electronic health record for patients with rare anaemias. This innovative tool will be used for epidemiological data extraction necessary for active surveillance of rare anaemias across Europe, for performing scientific studies, and for assisting all 28 member states in the planning and provision of suitable health services focusing on rare anaemias.



enerca.org



## e-LEARNING

FOR DISTANCE MEDICAL EDUCATION

---

This platform will be complementary to the on-site training courses that will be organized by ENERCA. It will be a useful tool for those people who are unable to attend the ENERCA courses. Access to this e-learning device will be user-friendly and it will offer a helpful aid for physicians, biologists and other professionals in their daily practice. As a result, this will reduce disparities in accessing high-level diagnosis and management for patients with rare anaemias.

## TELEMEDICINE

FOR APPROACHING DIAGNOSIS AND CLINICAL ADVICE

---

The ENERCA telemedicine platform will reduce inequalities in access to services necessary for diagnosis or follow-up of patients with rare anaemias. The platform will contribute to an improved expertise among health professionals by providing updated specialized health information, on-line discussion groups via peer-to-peer technical support. Moreover, the telemedicine platform will provide a repository of clinical cases and images categorized by SNOMED and ICD coding standards, which will be extremely useful for educational purposes.

## REACHING ALL THROUGH A COMPREHENSIVE DISSEMINATION STRATEGY

Project dissemination includes all those activities aiming to expand awareness of the ENERCA project, its website ([www.enerca.org](http://www.enerca.org)), and its activities and services in order to achieve the necessary critical mass to make the project fully successful and assure its sustainability.



- **On-site European training courses.** With e-ENERCA up and running, two European training courses will be organized, in collaboration with the European School of Haematology (ESH), and two European Symposia on Rare Anaemias will be held, with the collaboration and participation of local Patients' Associations.
- An **online application** based on the ENERCA White Book for the Recognition of Expert Centres will be designed. It will allow centres dealing with rare anaemias to assess their level of accomplishment based on ENERCA recommendations.
- Some of the contents generated by the network will be converted into **applications for smartphones and tablets**, thus providing new ways to access ENERCA services. The contents likely to become apps include a diagnosis flowchart, the ENERCA White Book Recommendations on diagnosis and clinical management, a telemedicine platform and an application for easy location of a health professional or a Patients' Association.
- In order to disseminate the contents of the website and increase the number of interested stakeholders, the ENERCA website will be strategically connected to **social networks**.
- Finally, the periodical **newsletter** will summarize the news and agenda items that are available on the ENERCA website and maximize the impact of the project activities across the group of stakeholders.

**The challenge of knowledge in rare anaemias: patient management varies between countries.**