

# ENERCA will pioneer the design of e-Health tools in rare anaemias for patients and experts

- *After 10 years of history, e-ENERCA is not just a continuation of ENERCA 3 but a clear step forward to the consolidation of the European Reference Network of Centres of Expertise on Rare Anaemias.*
- *e-ENERCA will develop during the next three years a pan-European e-health platform for teleexpertise/telediagnosis, electronic registry/epidemiological electronic health records and e-learning.*
- *Coordinated from IDIBAPS in Barcelona (Catalonia, Spain), the project joins the efforts of 26 expert centers in rare anaemias from 11 European countries. Cooperation between countries is crucial in the fight against rare diseases.*

The European Network for Rare and Congenital Anaemias ([ENERCA](#)) is a project funded by the European Commission through the Executive Agency for Health and Consumers (EAHC). e-ENERCA is the result of three previous phases (ENERCA 1, 2 and 3) that have been successfully developed during the last decade (2002-2012). During the next three years it will develop modern e-Health tools for a better management and knowledge of rare anaemias. As the previous phases of the project, e-ENERCA is coordinated by Prof. **Joan-LLuis Vives Corrons**, Head of the Red Cell Pathology Unit at the Hospital Clínic of Barcelona, and it pursues the consolidation of a European Reference Network in rare anaemias and focuses in professionals as well as in patients and their families. Coordinated from the Institut d'Investigacions Biomèdiques August Pi i Sunyer (IDIBAPS), the research Institute participated by the Hospital Clínic of Barcelona (Catalonia, Spain), e-ENERCA joins the efforts of 26 expert centers in rare anaemias from 11 European countries (ANNEX). The Kick-off Meeting of e-ENERCA was held on October 14<sup>th</sup> in Luxemburg.

Rare anaemias are rare diseases with prevalence in Europe under 5 cases per 10.000 individuals. Major forms require red blood cell transfusions and iron chelating therapy as main therapeutic options. Preventive programs aiming to epidemiological control and a better diagnosis and clinical management of major rare anaemias are crucial for decreasing the affected birth rate and achieving an efficient balance between disease morbidity and patient's life capacity. 1% of couples are at risk of having a newborn with a severe syndrome of haemoglobin, and over 330,000 children are born worldwide each year affected by one of these diseases, being the most common disorders sickle cell anemia and thalassemia syndromes. One of the most important aspects in the fight against rare diseases is the cooperation between countries, and here is where ENERCA is making a difference.

In its previous phases ENERCA worked on the promotion of best clinical and laboratory practices; The publication of ENERCA recommendations; The improving of continuous medical education; The empowerment of patients; The promotion of recognition of centres of

expertise and elaboration of a white book with this purpose. Now, while implementing the e-Health tools for all the EU member states, the innovative e-ENERCA goals will allow improving the impact of former actions in the prevention of major rare anaemias effects on the quality patient's life. e-ENERCA is not just a continuation of ENERCA 3, but a real step forward to the consolidation of the European Reference Network of Centres of Expertise on Rare Anaemias.

e-ENERCA will incorporate the innovative e-health information and communication technologies to create a pan-European interoperable e-health platform for teleexpertise/telediagnosis, electronic registry/epidemiological electronic health records and e-learning. As a result of the implementation of new e-health tools, e-ENERCA will create a new strategic collaboration environment for promoting the participation of European health professionals, researchers, medical education stakeholders and patients in the design and validation of health care services. This will be especially important for overcoming the current diagnostic difficulties for tackle rare anaemias, which cause remains unknown in more than 20% of the cases.

For further information:

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### **ANNEX: Centres participating in the e-ENERCA project**

**Associated Partners:**

Belgium:	Cliniques Universitaires de Bruxelles Hôpital Erasme
Cyprus:	Thalassaemia International Federation The Cyprus Foundation for Muscular Dystrophy Research University of Cyprus
France:	CHU de Montpellier European School of Haematology
Italy:	Foundation IRCCS Cà Granda Ospedale Maggiore Policlinico Milan
Spain:	Institut D'Investigacions Biomèdiques August Pi i Sunyer (IDIBAPS) Universidad del País Vasco / Euskal Herriko Uniberstitatea
The Netherlands:	University Medical Center Utrecht
United Kingdom:	King's College London West Hertfordshire Hospitals NHS Trust

**Collaborating Partners:**

Bulgaria:	National Centre of Haematological Transfusiology Sofia
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Cyprus:	Cyprus Thalassaemia Centre
France:	Centre Hospitalier Universitaire de Toulouse e-HEMATimage Hôpital Robert Debré
Germany :	Universität of Ulm
Greece:	Aristotelian University of Thessaloniki University of Athens
Italy:	Centro di Ricerca per l'Ingegneria Genetica Centro Nazionale Malattie Rare and Europlan Project Università degli Studi de Milano Università Vita-Salute San Raffaele University of Milan
Portugal:	Centro Hospitalar Coimbra
Spain:	Institute of Predictive and Personalized Medicine of Cancer