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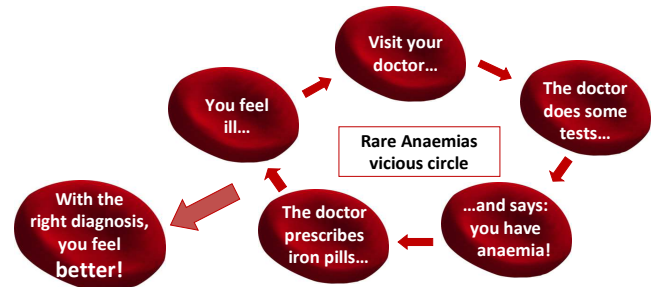


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On behalf ENERCA Consortium

The challenge of rare anaemias

Even though great advances have been achieved in the recent years, facing rare anaemias is still challenging:

- Ⓞ Poor implementation of comprehensive data collection and analysis systems
- Ⓞ Clinical care, prevention and diagnosis practices vary widely across countries
- Ⓞ Inequalities on access to diagnosis and therapies



European Network for Rare and Congenital Anaemias

e-ENERCA:
e-Health tools in rare anaemias for patients and experts

European reference networks (ERNs)

The focus of the ERNs is to facilitate improvements in access to diagnosis and delivery of high-quality, accessible and cost-effective healthcare in those medical conditions requiring a particular concentration of expertise or resources, particularly in medical domains where expertise is rare.

ENERCA is already working since 2002 to configure a trusted network of experts and centers against rare anaemias. The fourth phase of the project, e-ENERCA, focuses on the design of ICT tools to consolidate the network.

e-Learning

FOR DISTANCE MEDICAL EDUCATION

This platform will be complementary to the on-site training courses and useful for people who cannot attend the ENERCA courses. The access to this easy e-learning tool will contribute to lower inequalities in knowledge accessibility throughout Europe. This will contribute to help physicians and biologists improving their routine practice, decision making, and reduce inequalities in the access of high level diagnosis and management for patients with rare anaemias.

e-Registry

FOR EPIDEMIOLOGICAL SURVEILLANCE

Inventory of expert centres and epidemiological figures will provide ENERCA with comparable data at EU level. 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 an active surveillance of rare anaemias across Europe, performing scientific studies and assist all 28 member states in their planning and provision of relevant health services.

Telemedicine

FOR APPROACHING DIAGNOSIS AND CLINICAL ADVICE FOR RA IN DISTANT LOCATIONS

The ENERCA telemedicine platform will reduce the inequalities in the access to the facilities need for the diagnosis and management of patients with rare anaemias. The platform will contribute to an increased expertise of health professionals since it will provide specialized health information and on-line discussion groups to provide peer-to-peer support. The telemedicine platform will provide ENERCA with a repository of clinical cases and images categorized by SNOMED, the ICD classification with a high value for education purposes.

www.enerca.org

Reaching everyone by all means

Project dissemination includes all the activities aiming to expand the knowledge of ENERCA project, its website, and its activities and services in order to get the necessary critical mass to make the project fully successful and assure its sustainability.



e-ENERCA figures

Project co financed from the EU Public Health Programme
 Start date and duration of the project: September 1st 2013 – 3 years
 Total Cost: 1.955.289,30 €
 Co-Funding from the Commission: 1.163.274,39 €
 Leader Organization: IDIBAPS (Barcelona, Spain)
 Contact person: Prof. J.L. Vives Corrons
 Website: www.enerca.org
 Partners: 12 associated and 14 collaborating partners from 11 countries

