

6th EUROPEAN SYMPOSIUM ON RARE ANAEMIAS

1st Dutch-Belgian meeting for patients and health professionals

21st - 22nd November 2015
Amsterdam • The Netherlands



*This activity has been accredited
with 11 EBAH-CME credits*



Organizing committee

Joan Lluís Vives Corrons (ENERCA)
María del Mar Mañú Pereira (ENERCA)
Victoria Gutiérrez (ENERCA)
Richard van Wijk (UMCU)
Eduard van Beers (UMCU)
Béatrice Gulbis (ERASME)

Technical secretary

Victoria Gutiérrez
vgutierrez@clinic.ub.es
Phone +34934515950
FAX +34932271764
Barcelona, Spain
www.enerca.org

Scientific committee

Richard van Wijk- Universitair Medisch Centrum, Utrecht, the Netherlands
Eduard van Beers- Universitair Medisch Centrum, Utrecht, the Netherlands
Béatrice Gulbis- Hôpital ERASME Université Libre de Bruxelles, Belgium
Joan Lluís Vives Corrons- Hospital Clinic de Barcelona, Spain
María del Mar Mañú Pereira- Hospital Clinic de Barcelona, Spain
Patricia Aguilar-Martínez -Centre Hospitalier Universitaire de Montpellier, France
Michael Angastiniotis - Thalassaemia International Federation, Cyprus
Androulla Eleftheriou -Thalassaemia International Federation, Cyprus
Pilar Nicolás- Universidad del País Vasco, Spain
Carlos Romeo- Universidad del País Vaco, Spain

Support by an unrestricted educational grant from:

Platinum sponsor



Gold sponsor



Silver sponsor



Standard sponsor



The **6th European Symposium on Rare Anaemias** is an activity of the ENERCA project which aims to disseminate up-to-date knowledge and increase the public awareness about congenital and rare anaemias. As in other rare diseases, the recognition of expert centres, promotion of best practices and education and training of multidisciplinary health professionals teams are basic in order to serve patient needs, both in diagnosis and case management. Patients are always at the heart of ENERCA policies, like those of the Multi-ethnic organisation for patients with Sickle Cell and Thalassemia (OSCAR), Belgic Association of Thalassemia (ASBL), Aplastic Anaemia and Paroxysmal Nocturnal Hemoglobinuria (PNH) - rare blood disease community (HematosLife), Pyruvate Kinase Deficiency (PKD) Support Group, and Thalassemia International Federation (TIF).

In this respect, and specifically integrated in the framework of the 6th European Symposium on Rare Anaemias, the three organizers, ENERCA, led by CLINIC, UMCU and ERASME, with the support of OSCAR, ASBL, HematosLife, PKD Support Group and TIF have collaborated in setting up the **1st Dutch-Belgian meeting for patients and health professionals** in Amsterdam.

This year, transversal topics centered on common medical problems of patients with sickle cell, thalassaemia and other forms of haemolytic anaemia will be one of the key points of the symposium. These plenary sessions will deal with multiple converging lectures as well as with the state of the art therapy treatments and innovations in the field.

The second undeniable cornerstone for this symposium will be the special focus on the very rare anaemias, dealing intensively with PKD and PNH prevention, diagnosis, treatment and management. Furthermore, interactive sessions between patients and worldwide experts will develop a perfect atmosphere for brainstorming and sharing doubts among the attendants.

6th European Symposium on Rare Anaemias **1st Dutch-Belgian meeting for patients and health professionals**

ENERCA

The European Network for Rare and Congenital Anaemias (ENERCA), a project co-funded by the European Commission was set up in 2002 to help medical professionals and patients with rare anaemias by improving updated information and public health services through its website www.enerca.org. The main goal is assuring the same level of access for both health professionals and patients independently of their country of practice or origin and to decrease health inequalities in the field of rare anaemias. The new project e- ENERCA (2013-2016) will promote the recognition of Centres of Expertise at national level, a cornerstone as the nodes of the future European Reference Network (ERN) in Rare Anaemias to be implemented by the EU in the next future. Moreover, the new e-Health tool will include three main platforms a) electronic health records (EHR), for epidemiological surveillance, b) e-learning for on-line education and training and c) telemedicine for sharing experiences, contribute to an early diagnosis and facilitate chronic anaemia patient's care across Europe.



SATURDAY 21st November 2015

09:00-09:30	REGISTRATION	16:00-16:30	BREAK
09:30-11:00	WELCOME SESSION European Network for Rare and Congenital Anaemias Joan Lluís Vives-Corrons Dutch National Platform for Rare Diseases Paul Boom Belgian Platform for Rare Diseases (Belgian Authority for rare disease plan) Elfriede Swinnen European Commission – Rare Diseases Jaroslaw Waligora	16:30-18:00	PLENARY SESSION Common medical problems of patients with sickle cell, thalassaemia and other forms of haemolytic anaemia- II Chairperson: Bart Biemond Hormone related problems (Endocrinopathies and osteoporosis) Vincenzo de Sanctis Dyspnea Eduard van Beers Renal complications in sickle cell disease Swee Lay Thein
11:00-11:30	COFFEE BREAK		
11:30-13:00	PLENARY SESSION Common medical problems of patients with sickle cell, thalassaemia and other forms of haemolytic anaemia- I Chairperson: Eduard van Beers Iron overload and chronic blood transfusion Samantha Benghiat Vascular effects of hemolysis Gregory Kato Will your child be sick as well? Testing before pregnancy Béatrice Gulbis	18:00-18:45	POSTER WALK
		19:00-21:00	BUFFET GALA DINNER (Not included in the registration fee)
13:00-14:30	LUNCH		
14:30-16:00	PLENARY SESSION Pyruvate kinase deficiency (PKD) Chairperson: Richard van Wijk Introduction to PKD Richard van Wijk PKD National History Study Rachael Grace Activator treatment for PKD – Results from Phase 1 and overview of the Phase 2 trial Ann Barbier		

SUNDAY 22nd November 2015

09:00-10:30 PLENARY SESSION

Common medical problems of patients with sickle cell, thalassaemia and other forms of haemolytic anaemia- III

Chairperson: Béatrice Gulbis
Transition from paediatrics to adulthood:
Challenging but rewarding

Marjon Cnossen

Gene therapies in rare anaemias

Jose Carlos Segovia

Genetic tests for rare anaemias in the area of internet and of NGS (next generation sequencing)

Patricia Aguilar-Martinez

Developing a European registry for Rare Anaemias

Michael Angastiniotis

14:30-16:00 PLENARY SESSION

Comprehensive care for patients with sickle cell, thalassaemia and other forms of haemolytic anaemia

Chairperson: Patricia Aguilar-Martinez

Psychosocial effects of rare anaemias

Maaïke Metselaar-Eijgenraam

Role of nurses in treating patients with rare anaemias

Malou Ngalula Mujinga

Telemedicine and tele-expertise for rare anaemias

Béatrice Gulbis

Research and clinical trials, what are the rights of patients?

Pilar Nicolas

10:30-11:00 COFFEE BREAK

11:00-12:30 PLENARY SESSION

Paroxysmal Nocturnal Hemoglobinuria (PNH)

Chairperson: Rosario Notaro
Complement activation in hematological diseases. How innate immunity induces red blood cell destruction

Sacha Zeerleder

Paroxysmal Nocturnal Hemoglobinuria (PNH)

Introduction to PNH

Rosario Notaro

PNH in childhood

Marije Bartels

New treatment options for the atypical hemolytic uremic syndrome

Nicole van de Kar

16:00-16:15 CLOSURE OF THE SYMPOSIUM

Joan LLuis Vives-Corrons

12:30-14:00 LUNCH

14:00-14:30 HERMANN HEIMPEL HONORARY LECTURE

Achille Iolascon



Conference venue

PLANETARIUM AMSTERDAM

Kromwijkdreef 11
1108 JA Amsterdam
020 651 8585

OFFICIAL LANGUAGES

Dutch & English / Simultaneous interpretation will be available for the whole event

REGISTRATION

Go to <http://www.enerca.org/symposium2015> and complete the online registration form.

Hotel reservation

Reservations have to be self-made by attendants. There are three wonderful hotel options available. Choose the one you prefer, complete the Hotel Registration Form (available in <http://www.enerca.org/symposium2015>), and send it by mail or email to Planetarium Amsterdam (Subject ENERCA): e-mail: info@planetariumamsterdam.nl
Phone +31-20-651 8585

