

6th EUROPEAN SYMPOSIUM ON RARE ANAEMIAS

1st Dutch-Belgian meeting for patients and health professionals

21th -22th November 2015
Amsterdam • The Netherlands

**EHA-CME accreditation requested*



enerca
European Network for Rare
and Congenital Anaemias



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 (HematoLife), 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, UMCU and ERASME, with the support of OSCAR, ASBL, HematoLife, 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.

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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 21th November 2015

09:00-09:30 REGISTRATION

09:30-11:00 WELCOME SESSION

Chairperson: Maria del Mar Mañú
European Network for Rare and Congenital
Anaemias – Telemedicine

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

Jaroslav Waligora

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

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

Activator treatment for PKD – Results from
Phase 1 and overview of the Phase 2 trial

Ann Barbier

PKD National History Study

Rachael Grace

16:00-16:30 BREAK

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

Kidney dysfunction (Renal failure)

Swee Lay Thein

18:00-18:45 POSTER WALK

19:00-22:00 BUFFET GALA DINNER
(Not included in the registration fee)



SUNDAY 22th 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
Marjon Cnossen

Gene therapies in rare anaemias
Jose Carlos Segovia

New genetic tests, helpful or a waste of money?

Patricia Aguilar-Martinez

EU Registry

Michael Angastiniotis

14:30-16:00 PLENARY SESSION

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

Chairperson: Patricia Aguilar-Martinez
Psychosocial effects of rare anaemias

Patient perspective

Role of nurses in treating patients with rare anaemias

Nurse contact group

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

16:00-16:15 CLOSURE OF THE SYMPOSIUM

Joan LLuis Vives Corrons

11:00-12:30 PLENARY SESSION

Paroxysmal Nocturnal Hemoglobinuria (PNH)

Chairperson: Rosario Notaro
Introduction to PNH

Rosario Notaro

PNH and complement activation

Sacha Zeerleder

PNH in childhood

Marije Bartels

TTP/HUS

Nicole van de Kar

12:30-14:00 LUNCH

14:00-14:30 HERMANN HEIMPEL HONORARY LECTURE

Achille Iolascon

Poster
Abstract
Submission
Deadline:
November
6th,
2015

Conference venue

The symposium will be held in:

PLANETARIUM AMSTERDAM

Kromwijkdreef 11
1108 JA Amsterdam
020 651 8585

OFFICIAL LANGUAGES

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

Meeting registration

For health professionals:

Early registration (before 15th October 2015): 150€

Late registration (after 15th October 2015): 200€

For physicians in training registration fee: 100€

For patients and relatives (up to two family members) the registration is free

Buffet Gala dinner is not included in the registration fee: 50€

REGISTRATION

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

POSTER SUBMISSION

If you are willing to participate in the poster session please, send your **ABSTRACT** Communication up to 250 words no later than 6th November 2015 to the Technical Secretary (vgutierrez@clinic.ub.es)

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



Organizing committee

Joan Lluís Vives (ENERCA)
Mar Mañú (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
Joan Lluís Vives Corrons- Hospital Clinic i Provincial, Barcelona
María del Mar Mañú Pereira- Hospital Clinic de Barcelona
Patricia Aguilar-Martínez -Centre Hospitalier Universitaire de Montpellier
Michael Angastiniotis - Thalassaemia International Federation
Androulla Eleftheriou -Thalassaemia International Federation
Pilar Nicolás- Universidad de Deusto
Carlos Romeo- Universidad de Deusto

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