6th EUROPEAN SYMPOSIUM ON RARE ANAEMIAS

1st Dutch-Belgian meeting for patients and health professionals

21th -22th November 2015
Amsterdam • The Netherlands

enerca
European Network for Rare
and Congenital Anaemias

UMC Utrecht

CLÍNIC BARCELONA Hospital Universitari

Hôpital Erasme ULB

OSCAR

Pyruvate Kinase Deficiency

HematosLife

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 Thalassaemia (ASBL), Aplastic Anaemia and Paroxysmal Nocturnal Hemoglobinuria (PNH) - rare blood disease community (HematosLife), Pyruvate Kinase Defficiency (PKD) Support Group, and Thalassaemia 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, 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.

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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. 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.

www.enerca.org

SATURDAY 21th November 2015

09:00-09:30 REGISTRATION

09:30-11:00 WELCOME SESSION

Chairperson: Richard van Wijk

European Network for Rare and Congenital Anaemias – Telemedicine

Joan Lluis Vives Corrons

Dutch National Platform for Rare Diseases (Belgian Authority for rare disease plan)

Elfriede Swinnen

European Commission – Rare Diseases

Enrique Terol

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

ron overload and chronic blood transfusion

Domenica Cappellini

Vascular effects of hemolysis

Gregory Kato

Will your child be sick as well? Testing before pregnancy

Béatrice Gulbis

13:00-14:30 LUNCH

14:30-15:30 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

Sam Agresta

PKD National History Study

Rachel Grace

15:30-16:30 BREAK

16:30-17:30 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

17:30-18:30 POSTER WALK

19:00-22:00 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 anemias
Jose Carlos Segovia
New genetic tests, helpful or a waste of money?
Patricia Aguilar-Martinez
EU Registry
Michael Angastiniotis

10:30-11:00 COFFEE BREAK

11:00-12:30 PLENARY SESSION

Paroxysmal Nocturnal Hemoglobinuria (PNH)

Chairperson: Lucio Luzzatto

Introduction to PNH
PNH and complement activation
Sacha Zeerleder
PNH in childhood
Marije Bartels
TPH/HUS
To be confirmed

12:30-14:00 LUNCH

14:00-14:30 HERMANN HEIMPEL HONORARY LECTURE
Achille Iolascon

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

16:00-16:15 CLOSURE OF THE SYMPOSIUM
Joan LLuis Vives Corrons

Poster
Abstract
Submission
Deadline:
September
30th,
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 medical students registration fee:	100€

For patients and relatives the registration is free

Poster submission

If you are willing to participate in the poster session please, send your ABSTRACT Communication up to 250 words no later than 30th September 2015 to the Technical Secretary (vgutierrez@clinic.ub.es)

Organizing committee

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Mar Mañú (ENERCA)
Victoria Gutiérrez (ENERCA)
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Béatrice Gulbis (ERASME)

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Michael Angastiniotis - Thalassaemia International Federation
Androulla Eleftheriou -Thalassaemia International Federation
Pilar Nicolás- Universidad de Deusto
Carlos Romeo- Universidad de Deusto
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Domenica Cappellini- Università Degli Studi Di Milano

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