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

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Victoria Gutiérrez (ENERCA)
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Michael Angastiniotis- Thalassaemia International Federation, Cyprus
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Pilar Nicolás- Universidad del País Vasco, Spain
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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 Deficiency (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, 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.

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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 21st November 2015

09:00-09:30  REGISTRATION

09:30-11:00  WELCOME SESSION
European Network for Rare and Congenital Anaemias
Joan Lluis 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

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
PKD National History Study
Rachael Grace
Activator treatment for PKD – Results from Phase 1 and overview of the Phase 2 trial
Ann Barbier

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
Renal complications in sickle cell disease
Swee Lay Thein

18:00-18:45  POSTER WALK

19:00-21:00  BUFFET GALA DINNER
(Not included in the registration fee)
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

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

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
Chairperson: Patricia Aguilar-Martinez
Psychosocial effects of rare anaemias
Maaike 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

16:00-16:15 CLOSURE OF THE SYMPOSIUM
Joan LLuis Vives-Corrons
Conference venue
PLANETARIUM AMSTERDAM
Kromwijkdreef 11
1108 JA Amsterdam
020 651 8585

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

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