

Conference Programme

2nd Pan-European Conference on Haemoglobinopathies

Berlin, 13-14 March 2010

“Patients and health professionals together for optimal care”

in partnership with the Charité-Universitätsmedizin Berlin on the occasion of its 300th anniversary

Friday 12 March 2010 Venue: Courtyard by Marriott Berlin City Centre Hotel Axel-Springer-Strasse 55, Berlin 10117	
10:00–13:30 15:00–20:00	Advance registration – recommended for all delegates arriving on or before 12 March.

Day 1 of the Conference – Saturday 13 March 2010 Venue: Andel's Hotel Berlin Landsberger Allee 106, 10369 Berlin	
08:00–09:00	Registration
Opening Ceremony <i>Chairpersons: Androulla Eleftheriou and Gerhard Gaedicke</i>	
09:00–09:20	Welcome messages: Thalassaemia International Federation – <i>Panos Englezos, President of TIF</i> Charité-Universitätsmedizin Berlin – <i>Prof. Gerhard Gaedicke, Director of the Pediatrician Clinic</i> European Commission – <i>Mr John Dalli Commissioner for Health and Consumers (tbc)</i> German local/Federal health authorities – <i>Dr Guenter Jonitz, President, Berlin Medical Council</i>
Key presentations	
09:20–09:40	Current status of haemoglobinopathies in Europe: challenges and priorities in prevention and management – <i>Béatrice Gulbis</i>
09:40–10:00	Care of older patients with thalassaemia and sickle cell disease – <i>Paul Telfer</i>
Plenary 1 – Screening of Haemoglobinopathies <i>Chairpersons: Antonio Cao and Michael Angastiniotis</i>	
10:00 –10:20	Antenatal screening in England, Wales and Scotland – <i>Allison Streetly</i>
10:20 –10:40	Ethical and other challenges in the implementation of national prevention programmes in Europe: the impact of preventing haemoglobinopathies in Western and Northern Europe – <i>Antonio Cao</i>
10:40 –10:50	Application of capillary electrophoresis to the screening of haemoglobinopathies – <i>Piero C Giordano</i>

10:50–11:10	Coffee break
Plenary 2 – Clinical Management of Thalassaemia <i>Chairpersons: Aurelio Maggio, Renzo Galanello, Antonio Piga, Holger Cario and Loizos Pericleous</i>	
11:10-11:30	Blood transfusion therapy in thalassaemia major – <i>John Porter</i>
11:30-11:45	Iron overload – <i>Aurelio Maggio</i>
11:45-12:00	Iron overload: overview of treatment options: Deferasirox and Desferioxamine – <i>Maria Domenica Cappellini</i>
12:00-12:15	Iron overload: overview of treatment options: Deferiprone – Combination – <i>Renzo Galanello</i>
12:15-12:30	Adherence to therapies: health professional’s perspective – <i>Antonio Piga</i>
12:30-12:45	Adherence to therapies: patient’s perspective – <i>Chris Sotirelis</i>
12:45-13:00	Consistency of treatment and quality of life – the value of Guidelines – <i>Michael Angastiniotis</i>
13:00-13:20	Questions and answers
13:20–14:20	Lunch break
14:20-14:40	Total body chelation – <i>Ali Taher</i>
14:40-14:55	Update on survival in thalassaemia – <i>Paul Telfer</i>
14:55–16:40	Joint Workshop – Addressing patients’ concerns <i>Chairpersons: Panos Englezos and George Constantinou</i>
	Panel-led interactive discussion <i>Vincenzo de Sanctis, Ana Meo, Soroya Beacher, Roswitha Dickerhoff, Marco Bianchi, Yameen Rasul, Loizos Perikleous, Ofrah Muflani, Michael Michael, and Edith Aimiuwu</i> <ul style="list-style-type: none"> • Adolescence and Adult concerns - <i>Soroya Beacher</i> • Patient-centred healthcare - <i>Yameen Rasul</i> • Patient expert panel project - <i>Loizos Perikleous</i> • The role of the nurse – <i>Ofrah Muflani</i> • Social Integration – <i>Michael Michael</i> • The role of National and International Patients’ Associations – <i>Anton Skafi</i>
16:40–17:00	Coffee break
17:00–18:15	Joint Workshop – European Developments in the areas of Expert Centres and Registries
	Panel-led interactive discussion <i>Joan Lluís Vives Corrons, Antonio Piga, George Constantinou, Patricia Aguilar Martínez and Isabelle Thuret</i> <ul style="list-style-type: none"> • The value of patient registers – <i>Isabelle Thuret</i> • EU policies for the development and promotion of expert centres for rare diseases – <i>Michele Lipucci di Paola</i> • The ideal expert centre in haemoglobin disorders: the ENERCA project – <i>Joan Lluís Vives Corrons</i> • Patients’ expectations from expert centres – <i>George Constantinou</i>
20:30	Conference Dinner Andel’s Hotel Berlin, Landsberger Allee 106, 10369 Berlin

Day 2 of the conference – Sunday 14 March 2010
Venue: Andel's Hotel Berlin, Landsberger Allee 106, 10369 Berlin

09:00–09:20	Key Presentation: 2nd European Health Programme and EU Policies in Rare Diseases – <i>Dr Karl Freese, DG SANCO</i>
Plenary 3 – Clinical Management of Thalassaemia and Sickle Cell Disease <i>Chairpersons: Dora Bachir and Maria Domenica Cappellini</i>	
09:20–09:40	Pathophysiology of sickle cell disease – <i>Frederick Galacteros</i>
09:40–10:00	Management of sickle cell disease – <i>Marianne de Montalembert</i>
10:00–10:20	Transition from paediatric to adult medicine for thalassaemia and sickle cell disease – <i>Holger Cario</i>
10:20–10:40	Chronic viral hepatitis and liver disease in thalassaemia – <i>Vito Di Marco</i>
10:40–10:55	<i>Questions and answers – (End of Plenary 3)</i>
10:55–11:15	The value of networking in achieving common goals – <i>Alastair Kent</i>
11:15–11:25	<i>Discussion</i>
11:25–11:40	Coffee break
Plenary 4 – New Scientific Developments <i>Chairpersons: Gerhard Gaedicke and John Porter</i>	
11:40–12:00	Stem cell and cord blood transplantation in thalassaemia – <i>Emanuele Angelucci</i>
12:00–12:15	Gene therapy approaches – <i>Stefano Rivella</i>
12:15–12:30	Gene therapy approaches – <i>Giuliana Ferrari</i>
12:30–12:45	Alternative approaches – <i>Roberto Gambari</i>
12:45–13:15	<i>Questions and answers</i>
13:15–14:15	Lunch break
14:15–16:30	Parallel Workshops – Aspects of Holistic Management *

Thalassaemia

Chairpersons: *Vincenzo De Sanctis, Malcom Walker, Vasilios Demos*

- Bone disease in thalassaemia disease – *Ersi Voskaridou*
- Endocrine consequences in iron overload in thalassaemia major – *Vincenzo De Sanctis*
- Pathophysiology and management of thalassaemia intermedia – *Ali Taher*
- Cardiac consequences in thalassaemia major and intermedia – *Athanasios Aessopos*
- Cardiac T2*: calibration and relation to prognosis – *John Malcolm Walker*
- Monitoring of liver iron with Ferriscan -*John Porter*

*- coffee served in workshop rooms

Sickle Cell Disease

Chairpersons: *Marianne de Montalembert, Soroya Beacher, Frederick Galacteros*

- Pain management – *Paul Telfer*
- Neurological disorders/strokes: prevention and treatment – *Marianne de Montalembert*
- Acute medical emergencies – *Dora Bachir*
- Self-management education by patients for patients – *Soroya Beacher*
- Risk of severe haemolytic reactions in sickle cell disease and strategies to address them – *Dora Bachir*
- The effect of prolonged administration of hydroxyurea in children and adults with sickle cell disease – *Ersi Voskaridou*

* - coffee served in workshop rooms

16:30–17:00

Conclusions, Outcomes and the Way Forward

Panos Englezos, Androulla Eleftheriou, Michael Angastiniotis, John Porter