

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	
18:00–20:00	Advance registration for 2 nd Pan-European Conference on Haemoglobinopathies

Day 1: Saturday 13 March 2010 Venue: Charité Mitte Campus	
08:30–09:00	Registration
Opening Ceremony	
09:00–09:20	<p><i>Chairpersons: Androulla Eleftheriou and Gerhard Gaedicke</i></p> <p>Welcome messages:</p> <p>Thalassaemia International Federation – <i>Panos Englezos, President of TIF</i></p> <p>Charité-Universitätsmedizin Berlin – <i>Prof. Gerhard Gaedicke, Director of the Pediatrician Clinic</i></p> <p>European Commission – Commissioner – <i>tbc</i></p> <p>German local/Federal health authorities – <i>tbc</i></p>
Key presentations	
09:20–09:40	Future developments in the field of haemoglobinopathies: increasing role of the global network – <i>Sir David Weatherall</i>
9:40–10:00	Current status of haemoglobinopathies in Europe: challenges and priorities in prevention and management – <i>Béatrice Gulbis</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	<i>Questions and answers</i>
10:50–11:10	<i>Coffee break</i>

Plenary 2 – Clinical Management of Thalassaemia <i>Chairpersons: Aurelio Maggio, Renzo Galanello, Antonio Piga, Maria Domenica Cappellini 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	<i>Lunch break</i>
14:20-14:40	Commitment to Haemoglobinopathies– <i>tbc</i>
14:40–16:30	Joint Workshop – Addressing patients' concerns <i>Chairpersons: Panos Englezos and Androulla Eleftheriou</i>
	<p>Panel-led interactive discussion <i>Vincenzo de Sanctis, Evangelos Alexiou, Paul Telfer, Soroya Beacher, Marco Bianchi, Silvana Martins, Antonio Piga, German Rare Disease Alliance tbc, IAPO tbc, Yameen Rasul</i></p> <ul style="list-style-type: none"> • Adolescence and Adult concerns • Patient-centred healthcare • Patient expert panel project • The role of the nurse • Patients' information • The role of National and International Patients' Associations
16:30–16:50	<i>Coffee break</i>
16:50–18:00	Joint Workshop – European Developments in the areas of Expert Centres and Registries
	<p>Panel-led interactive discussion <i>Joan Lluís Vives Corrons, Roswitha Dickerhoff, Patricia Aguilar Martinez, George Constantinou, Isabelle Thuret</i></p> <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	Gala Dinner Venue: Courtyard by Marriott, Berlin City Centre Hotel

Day 2: Sunday 14 March 2010

09:00–09:20	Key Presentation: 2nd European Health Programme and EU Policies in Rare Diseases – Antoni Montserrat – tbc	
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	Care of older patients with thalassaemia and sickle cell disease – <i>Paul Telfer</i>	
10:40–11:00	<i>Questions and answers</i>	
11:10–11:20	<i>Coffee break</i>	
Plenary 4 – New Scientific Developments <i>Chairpersons: Sir David Weatherall, Gerhard Gaedicke and John Porter</i>		
11:20–11:40	Chronic viral hepatitis and liver disease in thalassaemia – <i>Vito Di Marco</i>	
11:40–12:00	Stem cell and cord blood transplantation in thalassaemia – <i>Emanuele Angelucci</i>	
12:00–12:20	Gene therapy approaches – <i>Stefano Rivella and Giuliana Ferrari</i>	
12:20–12:40	Alternative approaches – <i>Roberto Gambari</i>	
12:40–13:15	<i>Questions and answers</i>	
13:15–14:15	<i>Lunch break</i>	
14:15–16:30	Parallel Workshops – Aspects of Holistic Management *	
	<p>Thalassaemia <i>Chairpersons: Vincenzo De Sanctis, Malcom Walker, Yameen Rasul,</i></p> <ul style="list-style-type: none"> • Bone disease in thalassaemia disease – <i>Ersi Voskaridou</i> • Endocrine consequences in iron overload in thalassaemia major – <i>Vincenzo De Sanctis</i> • Pathophysiology and management of thalassaemia intermedia – <i>Ali Taher</i> • Cardiac consequences in thalassaemia major and intermedia – <i>Athanasios Aessopos</i> • Cardiac T2*: calibration and relation to prognosis – <i>John Malcolm Walker</i> • Monitoring of liver iron with Ferriscan – <i>John Porter</i> <p style="text-align: center;"><i>- coffee served in workshop rooms</i></p>	<p>Sickle Cell Disease <i>Chairpersons: Marianne de Montalembert, Soroya Beacher, Frederick Galacteros</i></p> <ul style="list-style-type: none"> • Pain management – <i>Paul Telfer</i> • Neurological disorders/strokes: prevention and treatment – <i>Marianne de Montalembert</i> • Acute medical emergencies – <i>Dora Bachir</i> • Self-management education by patients for patients – <i>Soroya Beacher</i> • Risk of severe haemolytic reactions in sickle cell disease and strategies to address them – <i>Dora Bachir</i> • The effect of prolonged administration of hydroxyurea in children and adults with sickle cell disease – <i>Ersi Voskaridou</i> <p style="text-align: center;"><i>* - coffee served in workshop rooms</i></p>
16:30–17:00	Conclusions, Outcomes and the Way Forward <i>Sir David Weatherall</i>	

List of speakers and chairpersons

Aessopos Athanasios Dr, Laikon General Hospital, University of Athens (Greece)
Alexiou Evangelos Mr., Greek Thalassaemia Federation (Greece)
Angastiniotis Michael Dr, Medical Advisor, TIF (Cyprus)
Angelucci Emanuele Dr, Haematology Department and Bone Marrow Transplant Centre (Italy)
Bachir Dora Dr, Henri Mondor Hospital, Paris (France)
Beacher Soroya Ms, OSCAR (Netherlands)
Bianchi Marco Mr, Associazione Lotta alla Talassemia di Ferrara (Italy)
Cao Antonio Dr, Istituto di Neurogenetica e Neurofarmacologia – CNR Cagliari, (Italy)
Cappellini Maria Domenica Dr, Università degli studi di Milano (Italy)
Cario Holger Dr, Ulm University Children’s Hospital (Germany)
Constantinou George Mr, TIF (UK)
Corrons Joan Lluís Vives Dr, Hospital Clinic i Provincial, Barcelona (Spain)
De Montalembert Mariane Dr, Necker-Enfants Malades Hospital, Paris (France)
De Sanctis Vincenzo Dr, Divisione Pediatrica Azienda, Ferrara (Italy)
Di Marco Vito Dr, University of Palermo (Italy)
Dickerhoff Roswitha Dr, University of Dusseldorf (Germany)
Eleftheriou Androulla Dr, Thalassaemia International Federation (Cyprus)
Englezos Panos Mr, Thalassaemia International Federation (Cyprus)
Ferrari Giuliana Dr, San Raffaele Hospital Milan (Italy)
Gaedicke Gerhard Dr, Charité Universitätsmedizin Berlin (Germany)
Galacteros Frédéric, Dr, Creteil (France)
Galanello Renzo Dr, Regional Thalassaemia Hospital Cagliari (Italy)
Gambari Roberto Dr, Thal-lab/University of Ferrara (Italy)
Gulbis Béatrice Dr, Hopital Erasme Université Libre de Bruxelles (Belgium)
Lipucci di Paola Michele Dr, University of Ferrara / Eurordis (Italy)
Maggio Aurelio Dr, Regional Centre for Thalassaemia (Italy)
Martinez Patricia Aguilar Dr, Centre Hospitalier Université de Montpellier (France)
Martins Silvana Ms, Erasmus MC (Netherlands)
Pericleous Loizos Mr, TIF (Cyprus)
Piga Antonio Dr, Thalassaemia Centre, University of Turin (Italy)
Porter John Prof, Royal Free and University College London Medical School (UK)
Rasul Yameen Mr, North of England Bone Marrow & Thalassaemia Association (UK)
Rivella Stefano Dr, Weill Cornell Medical College (USA/Italy)
Sotirelis Chris Dr, UK Thalassaemia Society (UK)
Streetly Allison Dr, NHS Sickle Cell & Thalassaemia Screening Programme (UK)
Taher Ali Dr, American University of Beirut Medical Centre (Lebanon)
Telfer Paul Dr, Royal London Hospital (UK)
Thuret Isabelle Dr, Centre Maladies Rares Thalassémie (France)
Voskaridou Ersi Dr, Laikon General Hospital, University of Athens (Greece)
Walker John Malcolm, Dr, University College London (UK)
Weatherall David Sir Prof, John Radcliff Hospital, Oxford (UK)