3rd PAN-EUROPEAN CONFERENCE ON HEMOGLOBINOPATHIES & RARE ANEMIAS
24-26 October 2012
GRAND RESORT HOTEL
LIMASSOL, CYPRUS
CONFERENCE PROGRAMME

UNDER THE AUSPICES OF THE CYPRUS PRESIDENCY OF THE EU COUNCIL
CO-SPONSORED BY THE EUROPEAN REGIONAL OFFICE OF THE WORLD HEALTH ORGANISATION (EURO)
ORGANISED BY THE THALASSAEMIA INTERNATIONAL FEDERATION (TIF) & THE MINISTRY OF HEALTH OF CYPRUS
IN COLLABORATION WITH THE EUROPEAN NETWORK FOR RARE ANEMIAS (ENERCA)
AND THE CYPRUS SOCIETY OF HEMATOLOGY (CSH)
AND THE CYPRUS ALLIANCE FOR RARE DISORDERS (CARD)
OFFICIAL CONFERENCE AIRLINE CARRIER - CYPRUS AIRWAYS
There is a silent threat in the non-transfused thalassemia patient

NTDT encompasses several thalassemia syndromes\textsuperscript{1,2}

- NTDT refers to a group of thalassemias that require intermittent or no blood transfusions\textsuperscript{1,2}
- It fits anywhere between mild to severe on the thalassemia spectrum\textsuperscript{3,4}

Common types of NTDT include\textsuperscript{2,3}:
- Thalassemia intermedia,
- HbE/\(\beta\)-thalassemia, and
- HbH/\(\alpha\)-thalassemia

NTDT affects the thalassemic belt and beyond\textsuperscript{2,4,5}

- The highest prevalence occurs in people from\textsuperscript{2,4,5}
  - The Mediterranean
  - The Middle East
  - South and Southeast Asia
- Immigration has increased the prevalence of NTDT in both the United States and Europe\textsuperscript{6,7}

Iron overload develops over time from two different sources

- Patients with NTDT primarily develop iron overload in the liver through increased gastrointestinal absorption and secondarily through intermittent transfusions\textsuperscript{8}
Look beyond serum ferritin of 1000 ng/mL

In NTDT, even patients with serum ferritin below 1000 ng/mL could be at risk for iron overload. As iron primarily accumulates in the liver in NTDT patients, high liver iron concentration (LIC) is generally seen with low serum ferritin levels. LIC is a good marker of iron burden and liver MRI should be the preferred diagnostic tool.

The Iron Health Alliance is here to help
You can learn more about NTDT through the Iron Health Alliance at www.ironhealthalliance.com.

MESSAGE FROM THE MINISTER OF HEALTH OF THE REPUBLIC OF CYPRUS AND THE PRESIDENT OF THE THALASSAEMIA INTERNATIONAL FEDERATION

On behalf of the organizers, the Ministry of Health of the Republic of Cyprus and the Board of Directors of the Thalassaemia International Federation (TIF), we feel extremely privileged to extend a warm welcome to you all to the 3rd Pan European Conference on Haemoglobinopathies and Rare Anaemias, held on 24-26 October 2012, in Limassol, Cyprus.

The Conference has been placed under the auspices of the Cyprus Presidency of the EU Council and is organised with the official support of the Ministry of Health of the Republic of Cyprus. Furthermore, the event is organised in collaboration with the European Network for Rare Anaemias (ENERCA), the Cyprus Society of Haematology (CSH) and the Cyprus Alliance for Rare Diseases (CARD).

With the assumption of the EU Presidency in the second half of 2012 (June - December) we believe that a unique opportunity is presented for us to share with other member states, and in particular the EU medical and patients communities in the field, the success story of Cyprus, with regards to the control of haemoglobin disorders.

Constituting a congregation of the most important actors in the field of haemoglobin and rare anaemias in Europe, the 3rd Pan-European Conference seeks to continue TIF’s internationally renowned Educational Programme. The Conference is expected to be the largest regional educational event organised in Europe on this topic.

A truly inspiring event, the Conference brings together stakeholders from 27 Member States to discuss avenues of action to tackle health inequalities across the EU and a growing public health burden of chronic and rare diseases in Member States, with a particular focus on patient rights as well as new and upcoming policies that are directly or indirectly related to health and quality of life. The programme includes an entire day of key overviews on the control, prevention, clinical management and cure of haemoglobin disorders and rare anaemias while during the second day a wide range of medical and scientific disciplines will be covered in parallel sessions. Very importantly sickle cell disease and rare anaemias will be comprehensively included in these sessions. As expected the patients perspective and contribution during the two days will be strongly pronounced.

We are also delighted to announce in addition, the launching of five (5) new important publications; Four prepared by TIF: (1) Prevention of Thalassaemias and other haemoglobin disorders (Vol. II) Updated Edition, (2) Thalassaemia Guidelines for Acute Complications (3) Guidelines for Thalassaemia Intermedia, and (4) Nurses Guidelines for the Care of Thalassaemia Patients. A fifth publication prepared in the context of the ENERCA project - the White Book on Networks of Reference Centres for Haemoglobin Disorders and Rare Anaemias will also be ready for launching in the course of this conference.

We encourage individual patients, patient organizations, healthcare professionals, carers, researchers, public health officials and policy-makers from all levels - national, regional and EU - to enjoy this Conference which we are more than sure will provide an exceptional forum to everyone for exchanging of knowledge and experience, but also for creating networks of collaboration and friendships!

‘Building on knowledge and experience’ is the motto of our Conference.

The cosmopolitan yet relaxing environment of Limassol, with state-of-the-art conference facilities, and a 16km beachfront that overlooks the Mediterranean Sea complemented, by an exciting social program that promises to make this Conference a truly unforgettable experience!

We very much look forward to meeting you all in Limassol, to build together on existing and new knowledge and experience, in a joint effort to contribute towards a better future for our European patients.

Cordially,

Dr. Stavros Malas
Minister of Health
Republic of Cyprus

Panos Englezos
President
Thalassaemia International Federation
Under the auspices of Cyprus Presidency of the EU Council
Organised by Thalassaemia International Federation (TIF) and the Ministry of Health of Cyprus
In collaboration with the European Network for Rare Anaemias (ENERCA)
Co-sponsored by the European Regional Office of the World Health Organisation (EURO)
With the support of the Cyprus Society of Haematology (CSH) and the Cyprus Alliance for Rare Disorders (CARD)

Conference Chairpersons
Dr Stavros Malas | Minister of Health, Cyprus
Panos Englezos | TIF President

COMMITTEES

I. ORGANISING COMMITTEE

Chairperson
Mrs Elsi Christofia | First Lady of Cyprus

Conference Coordinators
Androulla Eleftheriou | Executive Director, TIF
Michael Angastiniotis | Medical Advisor, TIF
Phoebe Katsouris | Marketing & Conference Advisor, TIF

II. SCIENTIFIC ADVISORY COMMITTEE

Honorary Chairperson
Titos Christofides | Under Secretary of State, Cyprus

Chairpersons
Sir David Weatherall | Emeritus Professor of Haematology, University of Oxford, Founder of the Weatherall Institute of Molecular Genetics, United Kingdom
Dimitris Loukopoulos | Emeritus Professor of Haematology, 1st Department of Medicine at the University of Athens, Greece
Christos Kattamis | Emeritus Professor of Paediatrics, University of Athens, Aghia Sophia Children's Hospital, Greece
J.L. Vives Corrons | Professor of Haematology, Hospital Clinic i Provincial, Barcelona and Coordinator of the European Network for Rare Anaemias (ENERCA) EU funded project, Spain
Marios Antoniades | President of the Cyprus Society of Haematology, Cyprus

MEMBERS

European Commission
Antonio Montserrat | Policy Officer for Rare Diseases at the Directorate of Public Health, EU

Eurordis
Yann Le Cam | Chief Executive Officer for the European Organisation for Rare Diseases - EURORDIS
Michelle Lipucci di Paola | Member of the European Organisation for Rare Diseases - EURORDIS

Cyprus
Soteroulla Christou | Coordinator of the Cyprus Thalassaemia Services
Adonis Ioannides | Clinical Geneticist, Course Director, St George’s University of London Medical Programme at the University of Nicosia
Marina Cleanthous | Director of the Thalassaemia Unit, Cyprus Institute of Neurology & Genetics (CING)

Italy
Maria Domenica Cappellini | Professor of Haematology, Department of Medicine and Medical Specialties, Istituto di Ricovero e Cura a Carattere Scientifico (IRCCS) Ca’ Granda Foundation Maggiore Policlinico Hospital, Milan
Umberto Rossi | President of the European School of Transfusion Medicine (ESTM)

Lebanon
Ali Taher | Professor of Haematology, Director of Department of Internal Medicine, American University of Beirut - Medical Centre

Turkey
Duran Canatan | Professor of Paediatric Haematology, Suleyman Demirel University, Isparta, President of the Thalassaemia Federation Turkey
Yesim Aydinok | Professor of Paediatric Haematology, Ege University, Faculty of Medicine, Izmir

United Kingdom
John Porter | Professor of Haematology, Head of the Thalassaemia and Sickle Cell Unit, Haematology Department, University College London

III. PATIENTS’ ADVISORY COMMITTEE

Chairpersons
Loizos Pericleous | TIF Board Secretary, past President of the Cyprus Anti-Anaemia Association
George Constantinou | TIF Board Member, Assistant Treasurer
Angelo Loris Brunetta | TIF Board Member, President of Associazione Ligure Thalassemici Onlus, Italy
Christina Stefanidou | TIF Board Member, Member of the Greek Thalassaemia Federation, Greece

MEMBERS

Belgium
Avgoustas Avgoustopoulos | President of the Association Belge de Thalassemie ASBL

Bulgaria
Dragomir Slavev | President of Thalassaemias Organisation in Bulgaria (OTB)
Ivan Ivanov | TIF Board Member, Vice-President of Thalassaemias Organisation in Bulgaria (OTB)

Cyprus
Natalia Michaelidou | President of the Cyprus Anti-Anaemia Association
Photis Eliades | Member of the Cyprus Anti-Anaemia Association

Greece
Vassilios Dimos | President of the Greek Thalassaemia Federation
Evangelos Alexiou | General Secretary of the Greek Thalassaemia Federation
Eleni Michalaki | Organisational Secretary of the Greek Thalassaemia Federation

Netherlands
Soroya Beacher | President of OSCAR Netherlands

Romania
Costin Radu Ganescu | President of Romania Association of Major Thalassaemia

United Arab Emirates
Saeed Al-Awadhi | TIF Board Member, Treasurer of the Emirates Thalassaemia Society, Financial Officer of the Sultan Bin Khalifa International Thalassaemia Award

Accreditation
The 3rd Pan-European Conference on Haemoglobinopathies and Rare Anaemias has been accredited with 12.5 CME Units from the European Haematology Association (EHA)
24 OCTOBER 2012 / WEDNESDAY / GRAND HALL - HALL A & HALL B

15.00 - 15.30  Welcome Coffee

15.30 - 16.30  Opening Ceremony
Panos Englezos | President of the Thalassaemia International Federation
Message by H.E. the President of the Republic of Cyprus will be read by Dr Titos Chrystofides | Under Secretary to the President
Jaroslaw Waligora | Directorate - General for Health & Consumers
JL Vives Corrons | Coordinator of The European Network for Rare and Congenital Anaemias
H.H Sheikh Zayed Bin Sultan Khalifa Al Nahyan | Chairman of Sultan Bin Khalifa International Thalassaemia Award
Charalampos Bakirtzis | Anastasios G. Leventis' Foundation
Richard Bergström | Executive Director of the European Federation of Pharmaceutical Industries & Associations
Launching of TIF’s new publications | Androulla Eleftheriou, Executive Director Thalassaemia International Federation

Key Note Speeches
Chairpersons  Panos Englezos & Dimitris Loukopoulos

16.30 - 17.00  Breakthroughs in haematology | Ulrich Jaeger
17.00 - 17.15  Archaeological medical findings in Cyprus | Demetris Michaelides
18.00 - 19.00  Welcome Cocktail

25 OCTOBER 2012 / THURSDAY / GRAND HALL - HALL A
SCIENTIFIC PROGRAM - PLENARY SESSION

09.00 - 11.00  Session 1: Scientific Overviews
Chairpersons  Christos Kattamis & Mahmoud Taleb Al Ali
Thalassemia - a dreadful disease turned to a chronic condition | Dimitris Loukopoulos
The metabolic effects of excess iron & its assessment | Ioav Z. Cabantchik
Genetic/ metabolic defects of iron metabolism & rare anaemias | Clara Camaschella
Iron Load | Aurelio Maggio
Iron Monitoring & treatment | Renzo Galanello
11.00 - 11.30  Coffee Break

11.30 - 12.30  Session 2: Cardiology
Opening Statement by Commissioner Androulla Vassiliou
Chairpersons  Renzo Galanello & John Porter
Pathophysiology of cardiovascular disease in rare anemias | Athanasios Aessopos
Cardiac arrhythmia: the emerging cardiovascular complication | Malcolm Walker
12.00 - 12.30  Satellite Symposium
Improving mortality in thalassemia - What’s behind the progress?
Chairpersons  Marios Antoniades & Antonis Kattamis
Welcome and introduction
Reducing morbidity and mortality in thalassemia - Progress made and remaining challenges | Ali T Taher
Optimizing treatment and managing complications in pediatric patients | Antonis Kattamis
Advances in the management of cardiac iron overload | John B Porter
Liver complications in thalassemia - Significance of liver iron overload, monitoring and management | Pierre Brisot
Interactive discussion and close
14.00 - 15.30  Lunch

15.30 - 17.00  Session 3: Non - Transfusion Dependent Thalassaemias (NTDT)
Chairpersons  Androulla Eleftheriou & Merhan Karimi
Epidemiology & Definitions | Androulla Eleftheriou
Recent Advances in Molecular Understanding of NTDT | Renzo Galanello
Hypercoagulability & thrombosis | Maria Domenica Cappellini
Iron Overload in NTDT | Khaled Musallam
Approaches to management of β - thalassaemia Intermedia | Ali Taher
Approaches to management of Hb-E / β thalassaemia and α syndromes | Vip Viprakasit
17.00 - 17.30  Coffee Break

17.30 - 18.15  Session 4: Prevention strategies in Haemoglobin Disorders
Chairpersons  Erol Baysal & Dimitris Loukopoulos
Prevention of Haemoglobinopathies | Dimitris Loukopoulos
Approaches to Overview of technical methods of prevention | Marina Kleanthous
21.30  Gala Dinner at Grand Resort Hotel
25 OCTOBER 2012 / THURSDAY / GRAND HALL - HALL B & HALL C
PATIENTS' PROGRAMME - PLenary Session

09.00 - 11.00
Session 1
Chairpersons: Panos Englezos & Ivan Ivanov

- Premature ageing of patients with Thalassaemia/Haemoglobin disorders
  | Michael Angastiniotis / Natalia Michaelidou
- Bone disease, osteoarthritis and pain
  | Ratna Chatterjee / Loris Brunetta
- Pain management
  | Paul Telfer / Soroya Beacher
- Patient - centred services
  | Farrukh Shah / Costin. Ganescu

11.00 - 11.30
Coffee Break

11.30 - 13.00
Session 2
Chairpersons: Riyad Elbard & Aggie Michael

- Challenges in personal relationships
  | Photis Eliades
- Are rare anaemias a disability?
  | Anton Skafi
- Doctor/Patient Relationship in Chronic Conditions
  | Soteroulla Christou
- Discussion

13.00 - 14.00
Session 3
Chairpersons: Saeed Al Alwadhi, Soteroulla Christou & Ahmet Varoglu

- Fertility and pregnancy
  | Rekha Bajoria / Tomassina Iorno
- Hypogonadism & Fertility in men
  | Nicos Skoridis

14.00 - 15.30
Lunch

15.30 - 17.00
Session 4
Chairpersons: Michael Michael & Duru Malyali

- Pulmonary Hypertension
  | Dimitrios Farmakis
- Renal Complications in Haemoglobinopathies
  | Miguel Abboud
- Liver Disease & thalassaemia
  | Geoffrey Dusheiko / George Constantinou

17.00 - 17.30
Coffee Break

17.30 - 18.00
Session 5
Chairpersons: Robert Ficarra & Loizos Pericleous

- Expert Patients Programme
  | Chris Sotirellis / Androulla Eleftheriou

21.30
Gala Dinner at Grand Resort Hotel

26 OCTOBER 2012 / FRIDAY / GRAND HALL - HALL A

09.00 - 10.45
Endocrinology
Chairpersons: Ratna Chatterjee & Ersi Voskaridou

- Diabetes in thalassaemia
  | Maria Barnard
- Fertility - Gonadal function in Thalassaemia
  | Nicos Skoridis
- Bone Disease in haemoglobin disorders
  | Ersi Voskaridou
- Pain and its management in Thalassaemia
  | Antonio Piga

10.45 - 11.15
Coffee Break

11.15 - 13.00
Blood
Chairpersons: Constantina Politis & Umberto Rossi

- Optimal Transfusion therapy in thalassaemia
  | John Porter
- Blood Safety, optimisation, new advances
  | Shubha Allard
- Pathogen Inactivation- New Progress
  | Antonio Piga

13.00 - 14.30
Lunch

14.30 - 16.00
Liver
Chairpersons: Maria Domenica Cappellini & Ali Taher

- Liver Disease & new advances in the management of chronic hepatitis (and new agents)
  | Geoffrey Dusheiko
- The contribution of the laboratory & more specifically of the molecular biology in the diagnosis, monitoring &
treatment of chronic viral hepatitis
  | Peter Karayiannis
- Cardiac & Liver assessment with available & upcoming technologies
  | Tim St. Pierre

16.00 - 16.30
Patients as Partners in Medicines R&D
Chairpersons: Mathew May

16.30 - 17.00
Coffee Break
26 OCTOBER 2012 / FRIDAY / GRAND HALL - HALL B

09.00 - 10.45  Sickle Cell Disease
Chairpersons  Ariel Koren & Paul Telfer

Overview & Pathophysiology | John Porter
Neurological Complications | Miguel Abboud
Guidelines for Adults in SCD | Paul Telfer

10.45 - 11.15  Coffee Break

11.15 - 13.00  ENERCA: 10 years of experience - Session I
Chairpersons  JL Vives-Corrons & Maria Mañú Pereira

ENERCA: 3: Experts centres and networking: Why are they important? | Michael Angastiniotis
Expert Services for rare anaemias across Europe - White Book II | Béatrice Gulbis
Education and training on rare anaemias: how to improve them? - Video presentation: Prevention of Haemoglobinopathies | P. Aguilar-Martinez

13.00 - 14.30  Lunch

14.30 - 16.30  ENERCA Session II
Chairpersons  JL Vives-Corrons & M. Mañú Pereira

Laboratory diagnosis of rare anaemias: Why quality assessment is important? | Barbara de la Salle
Current diagnostic approach and screening methods for hereditary spherocytosis | Paola Bianchi
Recent advances in the diagnosis and epidemiology of RBC enzymopathies in Europe | Richard van Wijk
Micro-mapping of very rare anaemias in Europe: the model of CDA | Hermann. Heimpel

16.30 - 17.00  Coffee Break

26 OCTOBER 2012 / FRIDAY / GRAND HALL - HALL C

09.00 - 10.45  Haemoglobinopathies in Europe - Issues of Concern
Chairpersons  Beatrice Gulbis, Patricia Aguilar-Martinez, Androulla Eleftheriou, JL Vives-Corrons & Stala Kioupi

Consistency & Adherence to Treatment - the Doctor, Nurses & patients’ role | Farrukh Shah & Loizos Pericleous
Ethnicity and Haemoglobinopathies | Simon Dyson
Health Impact of Haemoglobinopathies & its relationship to recent & old immigrant flows, a report from 10 European countries | JL Vives-Corrons

10.45 - 11.15  Coffee Break

11.15 - 13.00  Genetic Counselling & Laboratory Advances
Chairpersons  Mary Petrou & Begum Sadikoglu

Genetic Counselling | Adonis Ioannides
Laboratory Advances in Screening and Diagnosis | Androulla Kyrri
Advances in Molecular Diagnostics for Haemoglobinopathies | Joanne Traeger-Synodinos

13.00 - 14.30  Lunch

14.30 - 16.30  European Patient Organisations
Chairpersons  Androulla Eleftheriou & John Dart

European Organization of Rare Diseases | John Dart
Towards a more patient-centred healthcare system & effective services | Philip Chiroop
Progress in developing a Chronic Care Model and the contribution of HTA in improving health systems’ decisions | Alastair Kent
Cyprus Thalassaemia Association/ Ministry of Health Cyprus - DEEP Project | Evi Missouri - Khetab/ Soteroulla Christou

16.30 - 17.00  Coffee Break

26 OCTOBER 2012 / FRIDAY / GRAND HALL - HALL A & B

17.00 - 18.40  Plenary Session - Approaches to the cure of Haemoglobin Disorders
Chairpersons  Marina Kleanthous & John Old

Induction of HbF | Merhan Karimi
Decrease of α-chains | George Vasilopoulos
Development of model systems for β-thalassaemia | Jim Vadolas
Bone Marrow Transplantation | Lawrence Faulkner
Gene Therapy | Phillip LeBouch

18.40 - 19.00  Closing Remarks
Chairpersons  Androulla Eleftheriou & Dimitris Loukopoulos

The future of ENERCA: e-ENERCA | JL Vives-Corrons
Remarks by Chair of the Scientific Committee | Dimitris Loukopoulos
Conference Outcomes | Panos Englezos & Androulla Eleftheriou
FACULTY MEMBERS
Alphabetised by first name.

Adonis Ioannides  
Course Director, St George’s, University of London Medical Programme at the University of Nicosia, Cyprus

Aggie Michael  
Spouse, UK

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George Constantinou  Assistant Treasurer - Thalassaemia International Federation (TIF), UK Thalassaemia Society, UK
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J.L. Vives Corrons  Professor of Haematology, Hospital Clinic, University of Barcelona & Coordinator of the European Network for Rare Anaemias (ENERCA) EU funded project, Spain
Joanne Traeger-Synodinou  Assistant Professor of Genetics, Department of Medical Genetics, University of Athens, Choremeio Research Laboratory, ‘Agia Sofia’ Children's Hospital, Athens, Greece
John Dart  Deputy General Secretary of the European Organisation for Rare Diseases (EURORDIS)
John Old  Consultant Clinical Scientist and Honorary Reader in Haematology (Oxford University), National Haemoglobinopathy Reference Laboratory, Molecular Haematology, John Radcliffe Hospital, Oxford, UK
John Porter  Professor of Haematology, Head of the Thalassaemia and Sickle Cell Unit, Haematology, Department, University College London, UK
Jim Vadolas  Senior Research Fellow based at the Murdoch Children's Research Institute, Royal Children's Hospital, Melbourne, Australia and a member of the Executive Committee of the Australasian Gene Therapy Society, Australia
Khaled Musallam  Doctor, Department of Medicine and Medical Specialties, Istituto di Ricovero e Cura a Carattere Scientifico (IRCCS) Ca' Granda Foundation Maggiore Policlinico Hospital, Milan, Italy
Lawrence Faulkner  Paediatrician, Advisory Board Coordinator, Cure2children Foundation, Italy
Loizos Pericleous  Secretary - Thalassaemia International Federation (TIF), Cyprus Anti-Anaemia Association, Cyprus
Malcolm Walker  Consultant Cardiologist, Hatter Institute, University College London Hospital, London, UK
Maria Barnard  Lead Consultant in Diabetes & Consultant in Endocrinology and GIM and Caldicott Guardian, The Whittington Hospital, London, UK
Maria del Mar Mañú Pereira  Biologist, PhD, Red Cell Laboratory, Hospital Clinic, University of Barcelona & partner of the European Network for Rare Anaemias (ENERCA) EU funded project, Spain
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Michael Michael  Board Member - Thalassaemia International Federation (TIF), UK Thalassaemia Society, UK
Miguel Abboud  Professor of Paediatrics and Chairman at the Paediatrics and Adolescences Medical Centre of the American University of Beirut, Lebanon
Natalia Michaelidou  President of the Cyprus Anti-Anaemia Association, Cyprus
Nicos Skordis  Paediatric Endocrinologist, Division of Paediatric Endocrinology, Department of Paediatrics, Archbishop Makarios III Hospital, Nicosia, Cyprus
Panos Englezos  
President, Thalassaemia International Federation (TIF)

Paola Bianchi  
Head Biologist, Haematology Unit, Pathophysiology of Anaemia Unit, Foundation IRCCS Ca’ Granda Ospedale Maggiore Policlinico, Milan & partner of the European Network for Rare Anaemias (ENERCA) EU funded project, Italy

Patricia Aguilar-Martinez  
Medical doctor, Professor of Haematology, Centre Hospitalier Universitaire de Montpellier, qualified in Genetics, Coordinator of Montpellier Hospital Center of Expertise on rare iron disorders, member of WHO Expert Advisory Panel on Human Genetics & partner of the European Network for Rare Anaemias (ENERCA) EU funded project, France

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Petra Karayiannis  
Reader in Molecular Virology, Hepatology & Gastroenterology Section, Department of Medicine, Imperial College, London, UK

Philip Chircop  
Vice President of the Malta Blood Donor Association, Board member of European Patients Forum (EPF)

Phillippe Leboulch  
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POSTER ABSTRACT SESSION / 25TH OCTOBER 2012
POSTER SESSION: 09.00 - 18.00

Topic area 'blood'
S-303 treatment system for pathogen inactivation of red blood cell components (RBCs)
Erickson A., Hanson, D., Donnelly, B., Schott M., Arnold, D, Diaz T., Dupuis, T., Sawyer L., & Multi, N.
Safe blood transfusion for children with safe blood transfusion for children with haemoglobinopathies: are we delivering?
Hughes A. M. J. & Jayatunga R.

Topic area 'diagnostic & monitoring techniques'
T2-star (T2*) magnetic resonance imaging for assessment of kidney iron overload in thalassemic patients
Hashemieh M., Azarkeivan A., Akhlaghpooor S., Shirkavand & A., Sheibani K.
Detection of common beta-globin gene mutations in the Singapore population by high-resolution melt (HRM) analysis
Tan, Y., Roch. R., Law, H., Chatterjee R., & Bajoria, R.

Topic area 'epidemiology & prevention'
Premarital testing for β-thalassemia trait: Palestine experience
Younis, K
Exploring population awareness and attitude towards haemoglobinopathies premarital screening program in Dubai
Al Arrayed, K., Bajoria R., Belhoul, K. & Abu laban, J.
Carrier screening for inherited haemoglobin disorders among secondary school students and young adults in Latium, Italy
Epidemiology and prevention of thalassaemia and haemoglobinopathies among Latium immigrants: building on knowledge and experience at Anmi Onlus - Centro Studi Microcitemie of Rome (CSMR)
Family planning practice among families with children affected by β-thalassaemia major in southern Iran
Haghpanah, S., Johari, S., Parand, S., Reza Bordbar, M., & Karimi, M.
NHS sickle cell and thalassaemia screening programme
Latnovic, R.
Prevalence of haemoglobin disorder in Kuwaiti nationals attending premarital screening centers in Kuwait
Al-Fulaj, R. Gh. S., Marouf, R., Chatterjee R., & Bajoria, R.
Exploring sustainable follow-up strategies for thalassaemia screening, control and management: lessons from Bangalore, India
Dighe, N., Gambhir, S., Mathur, A., Eshwar, K., Biradar, M., & Jagannathan, I.
Newborn screening for sickle cell disease in Berlin – an anonymised study of 12000 newborns
Lobitz, S., Frömmel, C., Blankenstein, O., & Bajoria, R.
Haemoglobinopathy screening and prevention in northern Greece. A 10 year survey.
Spectrum of beta globin gene mutations in North Indian patients with thalassaemia major: application in prenatal diagnosis
Prevention of haemoglobinopathies in Northern Israel – YOTAM - A computerized program for running the database
Koren A., Palmor H., Levin C., Muskat H., Zaitzman I.

Topic area 'gene regulation & therapy'
Quantification of gamma-globin mRNA fold-increase in primary erythroid cultures: a parameter to predict the response of sickle cell and β-thalassemia patients to hydroxyurea treatment.
Pecoraro, A., Rigo, P., Troia, A., Calzolari, R., Acuto, S., Spina, B., Baiaante, E., Di Stefano, R., Renda, D., Maggio, A., Di Marzo, R.
Existence and frequency of molecular characteristics favouring foetal haemoglobin production in Cypriot thalassaemic patients
Sitarou, M.
Hbf induction
Karimi, M.

Rap-536 reduces ineffective erythropoiesis and corrects anemia in β-thalassemia
Suragani, R., Li, R., Scott, R., Matthew, P., Sherman, I., & Kumar, R.

Topic area 'iron'
Deferasirox (Exjade®) dose escalation achieves greater reductions in iron overload in non-transfusion-dependent thalassemia patients: 1-year results from the THALASSA study
Consistency of liver iron reduction with deferasirox (Exjade®) across subgroups of non-transfusion-dependent thalassemia patients from the 1-year THALASSA study

POSTER

Use of serum ferritin measurements to estimate liver iron concentration in non-transfusion-dependent thalassemia patients: analysis from the 1-year THALASSA study

Treatment of iron-overloaded pediatric patients with deferasirox (Exjade®): a 3-year follow up from the epic study

The comparison of the effects of desferrioxamine and deferasirox combination therapy with desferrioxamine monotherapy on liver iron overload of transfusion-dependent thalassemia patients
Sadikoglu, B., Yazman, D., Hocaoglu, M., Chatterjee, R., & Bajoria, R.

Cardiac iron overload in transfusion-dependent anemias: prevalence data from the cordelia trial comparing deferasirox (Exjade®) with deferoxamine for the removal of cardiac iron

Vitamin D deficiency and liver iron concentration in transfusion dependent hemoglobinopathies in British Columbia
Ezzat, H, Chatterjee, R & Bajoria, R.

Iron overload and its treatment at haemoglobinopathic patients in Albania
Kreka, M., Nastas, E., Qirjako, G., Kreka, B., Orendo, I., & Godo, A.,

Long-term safety and effectiveness of deferasirox (Exjade®) in pediatric patients aged 2–<6 years at enrollment: interim report from a 5-year observational study

Platelet function and chelation treatment in thalassaemia patients

Safety and efficacy of four year deferasirox treatment in patients with sickle cell disease
Vlachaki, E., Mainu, M., Bekiari, E., Vetsiou, E., Theodoridou, S., & Tsapas, A.

Topic area ‘rare anaemias’
Molecular analysis of rps19, rpl5 and rpl11 genes in Greek patients with diamond blackfan anemia
Delaporta, P., Sofocleous, C., Steiakaki, E., Polychronopoulou,S., Economou,M., Lossiva,L., Kostaridou,S., & Kattamis. A.

Congenital dyserythropoietic anemia type ii: molecular characterization in Sicilian patients.

POSTER ABSTRACT SESSION / 26TH OCTOBER 2012
POSTER SESSION: 09.00 - 18.00

Topic Area ‘Endocrine Complications’
Growth retardation among multitranfused thalassemic patients in thalassemic center of Babylon Governorate
Sherman Al-Watalify

Fructosamine In The Management Of Abnormal Glucose Metabolism In β-Thalassemia Major Patients
Pappa, C., Tzoumari, I., & Farmaki, K.

Comparison of lumbar spine and femoral Dxa t-score in contemporary measurements of thalassaemia major patients
Tzoumari, I., Pappa, C., & Farmaki,K.

Impaired Glucose Tolerance Test in β Thalassemia Major

Deferasirox Combined With Deferiprone May Improve Short Stature and Pubertal Maturation In Juvenile B-Thalassemia Major Patients
Kallistheni, K., Tzoumari, I., & Pappa, C.

Leptin levels in blood transfused β thalassemia patients
Levin, C., Admoni, O.,Yunes, M., Masalha, R., Tennenbaum Rakover, Y., & Koren, A.

Evaluation of glycemic abnormalities in β thalassemia major using continuous glucose monitoring system and oral glucose tolerance test
Abdel Daem, M., Yassin, M., Soliman, A., Elawwa, A., Kamzoul, R., Chatterjee R, & Bajoria, R.

Topic Area ‘Heart & Vascular Abnormalities’
Serial Echocardiographic Left Ventricular Ejection Fraction Measurements: A tool for detecting thalassemia major patients at risk of cardiac death
Microparticles: a new link between vascular wall stiffness and coagulation disturbances in chronic hemolytic anemia

Tantawy, A. A. G., Adly, A. A. M., Ismail, E., & Mamdouh, N.

Topic Area ‘Hepatological Complications’
Marked impact of IL28B genotype in the natural clearance of HCV-RNA clearance in patients with hemoglobinopathies
Piazza, A., Fecarotta, E., Renda, D., Agrigento, V., Scalfani, S., Madonia, S., Cottone, M., Maggio, A., & Renda, M.

Incidence of Hepatocellular carcinoma in patients with thalassemia who had Hepatitis C
Ansari, S., Azarkivan, A., & Farideh, H.

Treatment Of Chronic Viral Hepatitis In Thalassemia Major: Feasibility Of The Combined Therapy Ifn + Ribavirin
Ruffo, G.B, Capra, M., Cuccia, L., Gagliardotto, F., Marocco, M.R, Bronte, F., Di Marco, V., & Borsellino, Z.

Topic Area ‘Sickle Cell Disease’
Soluble CD163 levels as a novel risk marker for pulmonary hypertension in young sickle cell disease patients
Tantawy, A. A. G., Adly, A. A. M., & Ismail, E.

A systematic review of the literature to determine if prophylactic blood transfusion during pregnancy in sickle cell disease improves maternal and fetal outcomes
Defoe, L., Chatterjee, R., & Bajoria, R.

Adherence to prophylactic penicillin in patients with sickle cell disease - Alder Hey Children's Hospitals experience
Smith, L., Keenan, R., Barton, L., Chatterjee, R., & Bajoria R.

Cerebrovascular Events In Sickle Cell Disease Patients Treated With Hydroxyurea
Rigano, P., Calvaruso, G., Giangreco, A., Pantalone, G., Renda, D., Pecoraro, A., & Maggio, A.

The Outcome of Preoperative Transfusion Guideline On Sickle Cell Disease Patients At King Fahd Hospital-Jeddah (KSA)
Felemban, S, Qadi, A., Chatterjee, R., & Bajoria, R.

Admissions of sickle cell disease children in hospital de mataró: the last 6 years.
Cabot Dalmau, A., Cubero, S., Gómez, S., Vallduriola, I., Sánchez, V., & Trabazo Del Castillo, M.

Topic ‘Other’
Biomarkers of renal dysfunction in β-thalassemia major and intermedia patients
Tantawy, A. A. G., El Beblawy, N. S., & Adly, A. A. M.

Effects of treatment with curcuminoid and piperine derivative on subjects suffering from Haemoglobinopathy
Chowdhury, P., Chatterjee R., Bajoria R., Nabendu, C., Das Mani, K.

Adherence of Thalassemics To The Vaccination Program For The Flu And Streptococcus Pneumoniae
Kalpaka, A., Stefanidou, C., Vlahou, E., & Aggelaki, M.

B12 Vitamin Levels In Thalassaemia Patients
Kalpaka, A., Stefanidou, C., Vlahou, E., & Aggelaki, M.

The Outcome of Splenectomy In Beta Thalassaemia
Hadjigavriel, M, Simamonian, K., Christou, Y., Angastiniotis, M., Chatterjee., R & Bajoria, R.

HLA-typing by buccal swab to facilitate access to bone marrow transplantation globally. The Cure2Children Foundation preliminary experience

Clinical and haematological phenotype of the -101 c>t substitution in Greek beta-thalassaemia patients
Delapaorta, P., Stokidis, K., Traeger-Synodinos, J., Kanavakis, E., Kattamis, A.

Ex-vivo expansion of cord blood derived haematopoietic stem cells

Topic ‘Quality Care for Quality of Life’
Patient and Family Education in a multi-ethnic Bone Marrow Transplant Centre: Nurse’s Role
Dubali, M.

Disease complications of patients with sickle cells disease and quality of life outcomes at King Abdul Aziz University Hospital Jeddah, Kingdom of Saudi Arabia
Al Jaouni, S.K., & Halawa, T.
CONFERENCE FACILITIES & CAPACITIES

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