Conference Programme

11-12 November 2016
Le Royal Hotel, Amman

www.tifevents.org
If you don't plan on daily iron chelation...

...your plans may change.

You didn’t plan on having transfusion-dependent thalassemia. You may not like taking medicine every day. Some days you may forget.

It's important to take your iron chelation medicine every day as prescribed by your doctor.

Missed doses can cause iron levels in your body to rise over time. This can lead to serious health consequences, and even hospitalization.

Make a plan to help prevent iron overload:

- Combine taking your medicine with a daily activity, or use reminder, like a calendar, alarm, or mobile app
- Notify your doctor if you have side effects from your medicine
- Talk openly with your healthcare team about how you are feeling or questions you have

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Dear Friends,

We are privileged to cordially invite you to attend and participate in the upcoming 2nd MEGMA Conference on Thalassaemia and Other Haemoglobinopathies, covering the Middle East (ME), Gulf (G), Maghreb (M) and Africa (A) region. The Conference will take place on 11 - 12 November 2016 in Amman, Jordan.

Organised by the Thalassaemia International Federation (TIF) in collaboration with the Jordanian Thalassemia & Hemophilia Society and Ministry of Health of Jordan, this Conference promises to provide an outstanding opportunity for all involved stakeholders to bridge perspectives from various disciplines and to meet the challenges of improving the health and quality of life of those affected by haemoglobinopathies. This conference constitutes a unique forum for sharing knowledge and experiences and for building up new friendships, collaborations, partnerships and networks.

It is comprised of two parallel programmes, one for the health professionals and one for patients and their families and is expected to attract in total around 400 participants. Both the scientific and the patients/parents programme have been developed by national, regional and international experts, both health professionals and patients in a way as to cover in addition to overviews of existing treatment protocols all the new advances relevant to the care and cure of these disorders.

We are very privileged to have with us in this Conference grand personalities, known for their humanitarian but also scientific and medical activities.

Further to the contents of the 2nd MEGMA Conference on Thalassaemia and Other Haemoglobinopathies, we trust that your stay will be most enjoyable as Amman, and Jordan as a whole, offer unique beauty, culture, exceptional ambience and charm for all, and as such your stay is bound to leave in your minds an everlasting memory, and in your heart and soul an unforgettable experience.

We very much look forward to welcoming and seeing you all at this event, aiming to build a brighter future together for patients with haemoglobinopathies in the region and beyond!
Cordially,

Mr Panos Englezos  
President, Thalassaemia International Federation (TIF)

Dr Androulla Eleftheriou  
Executive Director, Thalassaemia International Federation (TIF)

Prof. Ali Taher  
Chairman of the Conference International Scientific Advisory Committee  
American University of Beirut Medical Center, Beirut, Lebanon

Dr Samir Faouri  
Chief Specialist of Paediatrics, Al-Bashir Hospital, Ministry of Health, Jordan

Dr Mustapha Al - Fallah  
President, Jordanian Thalassemia & Hemophilia Society

**Auspices**
Conference Committees

Conference Chair: Panos Englezos, President, Thalassaemia International Federation (TIF)

I. ORGANISING COMMITTEE

Coordinator: Androulla Eleftheriou, Executive Director, Thalassaemia International Federation (TIF)

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Medical Advisor, Thalassaemia International Federation (TIF)

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Essam Dohair
Director - Administration, TIF Regional Collaborating Office, H.H. Sheikh Sultan Bin Khalifa Al Nahyan Humanitarian & Scientific Foundation - UAE

II. INTERNATIONAL SCIENTIFIC ADVISORY COMMITTEE

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III. International Patients’ & Parents’ Advisory Committee

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Jordan Abdul Baset Mohd Merdas, Vice Chairman, Emirates Thalassaemia Society, UAE

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Narges Osman
Patients/event coordinator, Meena Welfare Association, Kabul, Afghanistan

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Esfahan Thalassaemia Society, Iran

Mehregan Hadipour
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Nour Abou Jaoude
Member of Chronic Care Centre, Lebanon

Anton Skafi
TIF Board Member, Thalassemia Patients Friends Society (TPFS), Palestine

Saeed Al Awadhi
TIF Board Member - Ass. Treasurer, Emirates Thalassemia Society, UAE

George Constantinou
TIF Board Member - Ass. Secretary, UK
<table>
<thead>
<tr>
<th>Name</th>
<th>Position and Affiliation</th>
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<tbody>
<tr>
<td>Jaffer Tooq</td>
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<td>WHO Regional Director for the Eastern Mediterranean, Egypt</td>
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<td>Fabrizia Bignami</td>
<td>EU Medical Lead/ Country Medical Lead France, bluebird bio, France</td>
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<td>Attending Cardiologist, University of Athens Medical School, First Department of Internal Medicine, Laiko Hospital, Second Department of Cardiology, Attikon Hospital, Athens, Greece</td>
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Atholl Johnston  Professor of Clinical Pharmacology, Barts and the London, School of Medicine & Dentistry, London, UK

Perla Eleftheriou  Consultant Haematologist, Joint Red Cell Unit, Haematology Department, University College London NHS Foundation Trust, London, UK

Robert Ficarra  Board Member - Thalassaemia International Federation (TIF), Cooley’s Anemia Foundation, USA
DAY 1 – FRIDAY 11 NOVEMBER 2016

08:30 – 09:30  Parallel Sessions: *Meet the Expert*

- **Hall Azure**
  - Pain Management in Sickle Cell Disease - J. Porter

- **Hall Hamurabi (3)**
  - Improving Adherence and Compliance in Chelation Therapy - F. Shah

- **Hall Hamurabi (1)**
  - Managing Osteoporosis in Thalassaemia - A. Piga

- **Hall Hamurabi (2)**
  - Hydroxyurea vs blood transfusion in SCD - S. Al Kindi

**Hall Ishtar 3**

09:00 – 10:30  **Session 1: Prevention & Diagnosis Globally & in the Region**

Chairpersons: E. Baysal & M. Angastiniotis

- 09.00 - 09.20  Prevention strategies/ policies in the Region M. Saffi
- 09.20 - 09.40  National prevention strategies across the globe M. Angastiniotis
- 09.40 - 10.00  Diagnostic dilemmas E. Baysal
- 10.00 - 10.30  Panel discussion

10:30 – 11:00  **COFFEE BREAK**
11:00 - 13:00  **Session 2: How I treat and monitor**  
Chairpersons: A. Taher & A. Beshlawy

11:00 - 11:30  How I treat and monitor β-thalassaemia  
J. Porter

11:30 - 12:00  How I treat and monitor sickle cell disease  
W. Jastaniah

12:00 - 12:10  Sickle cell disease - Experience from Bahrain  
J. Toq

12:00 - 12:30  How I treat and monitor non-transfusion dependent thalassaemia  
A. Taher

12:30 - 13:00  Panel discussion

13:00 - 14:30  **Lunch**

**Free Oral Presentations - Hamurabi Hall**

13:00 - 13:10  Evaluation of bone mineral density in patients with Haemoglobin H disease  
*Presenter: Z. Zahedi, Iran*

13:10 - 13:20  Osteoporosis among β-Thalassemia Patients in the West Bank of Palestine  
*Presenter: B. Karmi, Palestine*

13:20 - 13:30  Digital thermography and vascular involvement in thalassemia intermedia  
*Presenter: H. Moukhadder, Lebanon*

13:30 - 13:40  The Outcome of Preoperative Transfusion guideline on Sickle Cell Disease Patients at King Fahd Hospital-Jeddah  
*Presenter: S. Felemban, Saudi Arabia*

13:40 - 13:50  National Programme for Blood Genetic Disorders - Revisited  
*Presenter: M. El-Hazmi, Saudi Arabia*

13:50 - 14:00  Insight into the incidence and inheritance pattern of Beta-thalassemia in Lebanon  
*Presenter: J. Roumi, Lebanon*

14:00 - 14:10  Knowledge Attitude and Practices (KAP) among Patients on treatment of Thalassaemia in Maldives  
*Presenter: F. J. Saleem, Maldives*

14:10 - 14:20  “Thalassemia New challenges” / Palestine  
*Presenter: B. Karmi, Palestine*
14:30 - 15:30  **Session 3: Addressing emergency problems - Case Presentations**
Chairpersons: A. Adekile & J. Porter

14:30 - 15:00  β-thalassaemia major P. Eleftheriou
15:00 - 15:30  Sickle cell syndromes W. Jastaniah & S. Al Kindi

15:30 - 16:00  COFFEE BREAK

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16:00 - 17:30  **SATELLITE SESSION**
Chairpersons: O. Trad & A. Taher

16:00 - 16:15  Introduction
The history of chelation in Thalassemia: Do we need new modalities? H. Ezzat

16:15 - 16:45  Adherence to chelation treatment is lower than perceived: Myth or Reality?
- Adherence to chelation treatment: the clinical trial experience A. Kattamis
- Adherence to chelation treatment: the real world evidence A. Taher

16:45 - 17:05  Insights
New initiatives to improve adherence to chelation treatment: the Digital era A. Taher & A. Kattamis

17:05 - 17:30  Breaking News
Can the transition from the DT to FCT affect adherence? The Jadenu experience though the ECLIPSE trial A. Taher
OPENING CEREMONY

Master of Ceremonies: A. Eleftheriou

18:00 - 19:15  Opening remarks by:

H.E. the Minister of Health - Jordan, M. Al-Sheyyab

Sultan Bin Khalifa Humanitarian & Scientific Foundation

WHO Regional Director for the Eastern Mediterranean, A. Alwan

Former First Lady of Lebanon, M. Haraoui

Bait-Ul-Mal, A. Waheed

President of Jordanian Thalassemia & Hemophilia Association, M. Al-Fallah

President of Thalassaemia International Federation, P. Englezos

19:15 - 19:30  TIF Award Ceremony

KEYNOTE PRESENTATION

19:30 - 19:45  Current Status of Thalassaemia & Other Haemoglobinopathies in the Region A. Alwan (WHO - EMRO)

19:45 - 20:00  Current Status of Management & Care for patients with Haemoglobin Disorders globally & in the Region - The patients perspective R. Elbard
**DAY 2 - SATURDAY 12 NOVEMBER 2016 / Hall Ishtar 3**

**08:30 - 10:30**  
**Session 4: Multidisciplinary care**  
Chairpersons: M. Al - Fallah & A. Piga

- 08:30 - 08:50  
  Endocrine complications F. Shah
- 08:50 - 09:10  
  Cardiac complications D. Farmakis
- 09:10 - 09:30  
  Liver complications F. Shah
- 09:30 - 09:50  
  Use of MRI in monitoring: An Overview J. Porter
- 09:50 - 10:30  
  Panel Discussion

**10:30 - 11:00**  
COFFEE BREAK

**11:00 - 12:20**  
**Session 5: Reference Centres & Networking - Learning from the EU standards**  
Chairpersons: A. Eleftheriou & A. Taher

- 11:00 - 11:20  
  Building national reference centres and networking A. Piga
- 11:20 - 11:40  
  Use of e-registries in building and upgrading services M. Angastiniotis
  Experiences from the Region:
  - 11:40 - 11:50  
    Lebanon - M. Abi Saad
  - 11:50 - 12:00  
    KSA - Z. Al-Hawsawi
  - 12:00 - 12:10  
    Pakistan - A. Akhter
- 12:10 - 12:20  
  Discussion

**12:20 - 13:00**  
**Session 6: Emerging issues in patient care**  
Chairpersons: M. Hadipour & M. Hassan

- 12:20 - 12:40  
  Patients’ Rights: Legislation Globally & in the Region M. Hadipour
- 12:40 - 13:00  
  Challenges of migrations in the Region W. Slim

**13:00 - 14:00**  
LUNCH
### Session 7: New Approaches and Advances for CARE and CURE
Chairpersons: J. Porter & A. Al Jeffri

<table>
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<tr>
<th>Time</th>
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<tbody>
<tr>
<td>14:00 - 14:30</td>
<td>Gene therapy - an update on current trials</td>
<td>J. Ribeil</td>
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<tr>
<td>14:30 - 14:50</td>
<td>Haematopoietic stem cell transplantation</td>
<td>A. Al Jeffri</td>
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<tr>
<td>14:50 - 15:20</td>
<td>New drugs in thalassaemia management</td>
<td>A. Piga</td>
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<tr>
<td>15:20 - 15:30</td>
<td>Panel Discussion</td>
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<td>15:30 - 16:00</td>
<td>COFFEE BREAK</td>
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### Session 8: Ongoing Concerns Globally & in the Region
Chairpersons: A. Beshlawy & S. Hindawi

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<td>16:00 - 16:20</td>
<td>Blood and blood products: adequacy and safety</td>
<td>H. Abolghasemi</td>
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<tr>
<td>16:15 - 16:30</td>
<td>Haemovigilance approach for transfusion dependent patients</td>
<td>S. Hindawi</td>
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<tr>
<td>16:30 - 16:50</td>
<td>Medicinal products: accessibility and availability - Experience in Egypt</td>
<td>A. Beshlawy</td>
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<td>16:50 - 17:10</td>
<td>The use of safe and effective medicinal products in the Region</td>
<td>M. Hadipour</td>
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<td>17:10 - 17:30</td>
<td>Generic Drugs: How is their safety and effectiveness being secured in the EU and USA?</td>
<td>A. Johnston</td>
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<td>17:30 - 17:45</td>
<td>The importance of psychosocial support</td>
<td>E. Dohair</td>
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<tr>
<td>17:45 - 18:00</td>
<td>Closing remarks</td>
<td>P. Englezos, A. Taher, M. Al- Fallah &amp; A. Merdas</td>
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AMMAN, JORDAN • 11-12 NOVEMBER 2016
**PATIENTS & PARENTS PROGRAMME**

Programme Coordinator: F. Shah & P. Eleftheriou

### DAY 1 - FRIDAY 11 NOVEMBER 2016 / Hall Ishtar 1

<table>
<thead>
<tr>
<th>Time</th>
<th>Session 1: Health &amp; other care for Haemoglobin Disorders</th>
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<tbody>
<tr>
<td>10:30 - 13:00</td>
<td>Chairpersons: P. Englezos, A. Merdas &amp; M. Al - Fallah</td>
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<tr>
<td>10:30 - 11:00</td>
<td>What services should I expect to receive from my thalassaemia centre? L. Brunetta</td>
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<tr>
<td>11:00 - 11:30</td>
<td>What services should I expect to receive from my sickle cell disease centre? I. Al Hawsawi</td>
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<tr>
<td>11:30 - 11:45</td>
<td>Adherence to Treatment M. Al Asfour</td>
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<tr>
<td>11:45 - 12:00</td>
<td>Sharing best practices - Examples from Palestine, Lebanon &amp; Iran</td>
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<tr>
<td>12:00 - 12:15</td>
<td>How to work with government to achieve the right services R. Ficarra</td>
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<tr>
<td>12:15 - 12:30</td>
<td>How to work with healthcare professionals to achieve the right services A. Skafi</td>
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<tr>
<td>12:30 - 13:00</td>
<td>Q &amp; A - Common goals, challenges &amp; ways to address them</td>
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<tr>
<td>13:00 - 14:30</td>
<td>LUNCH</td>
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<thead>
<tr>
<th>Time</th>
<th>Session 2: The role of Patient Support Associations</th>
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<tbody>
<tr>
<td>14:30 - 16:00</td>
<td>Chairpersons: M. Abi Saad &amp; S. Al - Awadhi</td>
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<tr>
<td>14:30 - 14:50</td>
<td>Providing information and education to patients and families R. Elbard</td>
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<tr>
<td>14:50 - 15:10</td>
<td>Fund-raising for activities and services A. Merdas</td>
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<tr>
<td>15:10 - 15:30</td>
<td>Advocacy for policy development/ challenges G. Constantinou</td>
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<tr>
<td>15:30 - 16:00</td>
<td>Q &amp; A</td>
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<tr>
<td>16:00 - 16:30</td>
<td>COFFEE BREAK</td>
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</table>
### Session 2: New advances for CARE and CURE

**Chairpersons:** A. Piga & F. Bignami

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>16:30 - 16:50</td>
<td>New Advances in thalassaemia management A. Piga</td>
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<tr>
<td>16:50 - 17:10</td>
<td>Gene therapy - an update on current trials F. Bignami</td>
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<tr>
<td>17:10 - 17:30</td>
<td>Q &amp; A</td>
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</tbody>
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### OPENING CEREMONY

**Master of Ceremonies:** A. Eleftheriou

<table>
<thead>
<tr>
<th>Time</th>
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<tbody>
<tr>
<td>18:00 - 19:15</td>
<td>Opening remarks by:</td>
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<tr>
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<td>H.E. the Minister of Health - Jordan, M. Al -Sheyyab</td>
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<td>Sultan Bin Khalifa Humanitarian &amp; Scientific Foundation</td>
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<td>WHO Regional Director for the Eastern Mediterranean, A. Alwan</td>
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<td>Former First Lady of Lebanon, M. Haraoui</td>
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<td>Bait-Ul-Mal, A. Waheed</td>
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<td></td>
<td>President of Jordanian Thalassemia &amp; Hemophilia Association, M. Al-Fallah</td>
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<tr>
<td></td>
<td>President of Thalassaemia International Federation, P. Englezos</td>
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<td>19:15 - 19:30</td>
<td>TIF Award Ceremony</td>
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### KEYNOTE PRESENTATION

<table>
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<tr>
<th>Time</th>
<th>Event</th>
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<tr>
<td>19:30 - 19:45</td>
<td>Current Status of Thalassaemia &amp; Other Haemoglobinopathies in the Region A. Alwan (WHO - EMRO)</td>
</tr>
<tr>
<td>19:45 - 20:00</td>
<td>Current Status of Management &amp; Care for patients with Haemoglobin Disorders globally &amp; in the Region - The patients perspective R. Elbard</td>
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</tbody>
</table>
DAY 2 - SATURDAY 12 NOVEMBER 2016 / Hall Ishtar 1

08:30 - 10:00 TIF Board Meeting (by invitation only)

10:00 - 10:30 COFFEE BREAK

10:30 - 12:00 TIF Constitutional General Meeting (by invitation only)
10:30 - 10:35 1: President’s Welcome Message
10:35 - 10:45 2: Confirmation of quorum and declaration of opening of the meeting
10:45 - 11:00 3: Reading of the change (s) the Board suggests
11:00 - 11:10 4: Explanation of the procedures and voting
11:10 - 12:00 5: Outcome of voting Procedure and decision on the proposed changes in the Constitution

12:00 - 13:00 TIF General Assembly
12:00 - 12:05 1: President’s Welcome Message
12:05 - 12:15 2: Approval of the minutes of the previous General Assembly
12:15 - 12:20 3: Audited Accounts for the Year 2015
12:20 - 13:00 4: Any Other Business related to the General Assembly
  • Report on TIF’s activities of 2013-2016

13:00 - 14:00 LUNCH

14:00 - 18:00 *Common with the Scientific Programme* - see page 21
Where a 25-year legacy of innovation in chronic HEPATITIS C treatment\textsuperscript{1–3} meets AN UNWAVERING COMMITMENT TO THE TASK AT HAND

HEPATITIS C IS A SERIOUS BURDEN THAT CAN HAVE DIRE CONSEQUENCES\textsuperscript{4}

According to the World Health Organization, the human cost of hepatitis C–related liver diseases is staggering: It claims the lives of approximately 500,000 people per year.\textsuperscript{5} However, recent advances in care have led many to believe that elimination of hepatitis C is possible. MSD remains committed more than ever to providing innovative solutions for advancement of chronic hepatitis C treatment and to working towards the ultimate goal of hepatitis C elimination.

Learn more about how MSD is addressing the task at hand by visiting www.merckconnect.com

Blood transfusion - adequacy & safety:
Assessment of a Cohort of Beta Thalassemia Patients: New Challenges - Bradai M, Benmouaffek N.

Bone disease:

Osteoporosis among β-Thalassemia Patients in the West Bank of Palestine - Karmi B, Kharroubi A, Shamasna W, Saba E.

Which Pamidronate Protocol Is The Best for Treating Osteoporosis in Beta-Thalassemia Major? - Zafari M, Kowsariyan M.

Diagnostic & Monitoring Techniques:


Endocrine Complications:
The Association of Pancreatic MRI R2* with Fasting and 2-Hour Postprandial Blood Glucose among Thalassemia Major Patients in Indonesia - Wahidyat PA, Putriasih S.A, Adnani N.B.

The Saudi Experience on the Effects of Endocrine Complications and its Morbidity in Thalassemia - Al Jaouni S.K.

Epidemiology and prevention:

High Resolution Melting Analysis for Non-Invasive Prenatal Diagnosis of IVS-II-1 (G-A) Fetal DNA in Minor Beta-Thalassemia Mothers - Zafari M, Gill P, Kowsaryan M, Alipour A, Banihashemi A.


National Programme for Blood Genetic Disorders - Revisited - El-Hazmi M.


Epidemiology of B-thalassemia major in the Rabat Reference Center - Khattab M, Isfaoun Z, EL Kababri M, Kili A, El Khorassani M, Hessissen L.

Carrier Frequency of Alpha Thalassemia Mutations among Newborns in Northern Iran - Mahdavi MR, Kosaryan M, Karami H, Mahdavi M, Jalali H, Roshan P.

Fertility & Pregnancy:
Evaluation of marriage and childbirth in patients with non-transfusion dependent beta thalassemia major at Thalassemia Research Center of Sari, Iran - Zafari M, Kowsariyan M.

Gene Regulation & Therapy:
Beta Globin Gene Haplotypes Associated with Hemoglobin D-Punjab in Northern Iran - Jalali H, Mahdavi M, Kosaryan M, Karami H, Roshan P Maddahian F.

β-Globin gene cluster haplotypes of Hb D-Los Angeles in Mazandaran Province, Iran - Mahdavi M, Jalali H, Kosaryan M, Roshan P, Mahdavi M.

Heart & Vascular Abnormalities:
Prevalence of Pulmonary Hypertension in Patients with Thalassaemia Intermedia, A Single Center Experience - Badiei Z, Moughaddam H.M, Farhangi H, Shakeri R.

The Relationship between serum vascular endothelial growth factor (SVEGF) and beta thalassemia major - Farokhi F, Razaviyan J, Kosaryan M, Roudbari M, Reykande S.E, Aliasghariyan A, Dehghani M.


Kidney Injury Molecule-1 and Heart-Type Fatty Acid Binding Protein as Novel Early Markers of proximal and Distal Renal Tubular Dysfunction in Children with B-Thalassemia Major - Sherief L.M, El-Safy O.R, Zidan A, Youssef M.D, El-Sayed M.
**Hepatological Complications:**

**Iron Liver Toxicity Presenting as Hepatic Nodule in Major Beta Thalassemia Patient: A Case Report** - Lubis A.M.

**Decrease of Hepatitis C Burden in Patients with Transfusion Dependent Beta Thalassemia Major, Thalassemia Research Center, 1995 - 2014** - Kosaryan M, Aliasgharian A.

**HSCT – BMT:**


**Iron Overload & Management:**

**Iron chelation and liver disease healing activity of edible mushroom (Cantharellus cibarius), in vitro and in vivo assays** - Khalili M, Ebrahimzadeh M.A, Kosaryan M Abbasid A, Azadbakhta M.

**In Vivo Iron-Chelating Activity and Phenolic Profiles of the Angel’s Wings Mushroom, Pleurotus Porrigens (Higher Basidiomycetes)** - Khalili M, Ebrahimzadeh M.A, Kosaryan M.

**Combination of Deferoxamine/Deferiprone in Improving Cardiac, Liver and Pancreatic T2* in Twins With Beta Thalassemia Major and Severe Iron Overload: A Case Report** - Rahmartani L.D, Wahidiyat P.A, Sari T.T.


**Is There a Difference In Neutrophil Phagocytosis Among Different Iron Chelators?** - Sari TT, Akib AAP, Gatot D, Bardosono S, Hadinegoro SRH, Harahap AR, Idjradinata P.

**Urinary Iron Examination to Evaluate Iron Overload in Children with Thalassemia Major** - Wahidiyat P.A, Wijaya E.

**Safety of Deferoxsirox (Exjade) in Beta Thalassemia Patients with Serum Ferritin Less Than 1000** - Karimi M, Shourijeh Z.B, SezanehHaghpanah, Zahedi Z.
Miscellaneous:
Does Beta Thalassemia Increase the Incidence of Bells Palsy? - Al Jebori, S.S.

Refractive errors and ocular biometry components in thalassemia major patients - Heydarian S, Jafari R, Karami H.


“Thalassemia New challenges” / Palestine - Karmi, B.

New Developments in Thalassaemia:


Non-transfusion Dependent Thalassaemia:
RAP-536 (Murine Analog Of ACE-536/Luspatercept) Inhibits SMAD2/3 Signalling and Promotes Erythroid Differentiation by Restoring Gata-1 Function in a Murine Model of B-Thalassemia - Martinez P, Bhasin M, Li R, Pearsall S, Kumar R, Suragani R.


Psychosocial Support:
Qualitative Research on the Obstacles in Marriage and Reproductive Process of People with Transfusion Dependent Thalassemia - Hosoya S, Jamali G.R, Shahriari M.

Knowledge Attitude and Practices (KAP) among Patients on treatment of Thalassaemia in Maldives - Saleem F.J.

Attributional Styles in Adolescents with Transfusion Dependent Thalassemia - Suwanthol L, Sangpaypan T, Naknum P, Sanpakit, K.
Quality Care for Quality of Life:

Multifaceted Approach to Thalassemia Care & Management - Our Experience & Lessons Learned - Patil S, Kulkarni R, Kale V, Patil S, Tated N, Jain A.

Presentation of Thalassemia Ward in East Medical Special Center in Tehran and Clinical Challenges in Management of Thalassemic Patients in all Fields - Sabzechian M, Fallah R, Gholami M.


Sickle Cell Disease:

Hydroxyurea: An Effective Therapy to Avoid Splenectomy in Sickle Cell Disease and Thalassemia: Single Institute Experience in Saudi Arabia - Al Jaouni S.K.

Clinical & hematological profiles among Bahraini children with sickle cell disease - AlMukharraq H.


The Outcome of Preoperative Transfusion guideline on Sickle Cell Disease Patients at King Fahd Hospital-Jeddah (KSA) - Felemban S.R, Bajoria R, Alsawaf A, Chatterjee R, Qadi A.


My Personal Journey Through Hydroxyurea Therapy in Sickle Cell Disease During Pregnancy and Lactation - Shakir A.S.

= Oral & Poster
The Organising Committee of the 2nd MEGMA Conference on Thalassaemia and other Haemoglobinopathies would like to express their sincerest gratitude to the following sponsors for their support.

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Thalassaemia International Federation is an NGO founded in 1986 by a small number of patients and families representing National Thalassaemia Associations in Cyprus, Greece, UK, USA, and Italy, countries in which these diseases have been recognised as an important matter for public health and where the first programmes for prevention and management have been implemented.

To improve the survival and quality of life of patients with thalassaemia through the promotion and support of: education, advocacy and capacity building of patients’ and their families’ awareness and education programmes for the community collaboration with national, regional and international health authorities aiming to (a) prioritise thalassaemia on national, regional and International health agendas; (b) develop and implement national disease specific programmes for its effective control, prevention and holistic care, and research programmes and studies focused on the final, total cure (c) Establish equal access of every patient with thalassaemia to high quality health and social care services provided through truly patient-centred healthcare systems.

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