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PALERMO

Fondazione
FrancoePieraCutino
Guarire dalla
TALASSEMIA

# 1st International Working Group on Thalassemia:

## IS IT TIME TO REVISIT CLASSIFICATION OF THALASSEMIA SYNDROMES ?

*CAMPUS OF HEMATOLOGY*
*"Franco e Piera Cutino"*
*A.O.R. "Villa Sofia - V. Cervello"*
*Palermo (Italy)*

**September 15-16, 2017**

*Invited Chairs:*
**Antonis Kattamis, Aurelio Maggio, Khaled Musallam** *and* **Ali Taher**

*Organized by* **Prof. Aurelio Maggio**

***Dear all,***

*Thank you very much for accepting to join the International Working Group (IWG) on Thalassemia.*

*The main aim for establishing this IWG is to revisit the conventional thalassemia classification of severity (Thalassemia Major and Intermedia), owing to recent evidence suggesting the dichotomy may not be as distinct and in view of recent changes in patient management and identification of phenotypes based on transfusion-requirement.*

*In order to do that, we would need first to reach a consensus on the key factors to consider for such a revision, through a standard methodology and evidence grading system (e.g. GRADE by Guyatt et al., 2008). In this context, some thoughts to consider for defining disease severity through a new model, subject to discussion during the meeting, would be:*

**1)** *The quality/grade of evidence for the currently used criteria to differentiate thalassemia major versus intermedia at initial diagnosis:*

- *age of diagnosis (<2 vs >2 years old)*
- *Hemoglobin level (<7 vs >7 g/dl)*
- *growth failure (<3 percentile)*
- *Hemoglobin electrophoresis results*

**2)** *The risks versus benefits of including patients in transfusional regimens independent of age and hemoglobin level at onset of the disease, with periodical re-evaluation*

**3)** *The quality/grade of evidence for the currently used criteria to start iron chelation therapy*

- *age (2 years or older )*
- *transfusions (10-20 tx)*
- *serum ferritin level (> 1000 ng/mL)*
- *LIC >7 mg Fe/g (with age-related assessment limitations)*

**4)** *The wide spectrum of disease severity in patients currently labelled as thalassemia intermedia, with respect to pathogenesis and clinical complications profile.*

*We would need to identify those factors that determine severity of disease and then find a method to quantify those factors (based on existing literature or new research) to come up with different levels of severity, formulating a scoring system which should be independent of local health systems. Until our meeting, you can think of those pathophysiologic and clinical indicators that you would recommend to define severity of thalassemia syndromes. It should be noted that a similar exercise has been recently conducted by Cappellini and colleagues (EJIM 2016) who developed a scoring system for non-transfusion-dependent thalassemia. We can use this as a starting model to go through the same exercise for all thalassemia phenotypes. Furthermore, we will discuss how to validate this scoring system. To do that we can either get a large data set and look at the association between the newly developed scoring/classification system against outcomes.*

*Finally, if consensus is reached we will aim to submit our results to a leading international journal.*

*Best regards*

*Antonis Kattamis, Khaled Musallam, Ali Taher, & Aurelio Maggio*

## *Faculty:*

| | | | |
|---|---|---|---|
| *Kunle Adekile* | *Kuwait* | *Ibrahim Hishamshah* | *Malaysia* |
| *Saqib Hussain Ansari* | *Pakistan* | *Mehran Karimi* | *Iran* |
| *Yesim Aydinok* | *Turkey* | *Antonis Kattamis* | *Greece* |
| *Caterina Borgna Pignatti* | *Italy* | *Aurelio Maggio* | *Italy* |
| *Marie Charlotte Bouesseau* | *Switzerland* | *Paolo Moi* | *Italy* |
| *Maria Domenica Cappellini* | *Italy* | *Alessia Pepe* | *Italy* |
| *Marina Cavazzana* | *France* | *Antonio Piga* | *Italy* |
| *Adriana Ceci* | *Italy* | *John Porter* | *UK* |
| *Lakhmir S. Chawla* | *USA (sp. La Jolla)* | *Eliezer Rachmilewitz* | *Israel* |
| *Alan Cohen* | *USA* | *Paolo Ricchi* | *Italy* |
| *Shahina Daar* | *Oman* | *Farrukh Shah* | *KSA* |
| *Vito Di Marco* | *Italy* | *Alok Srivastava* | *India* |
| *Amal El-Beshlawy* | *Egypt* | *Tim St Pierre* | *Australia* |
| *Aldo Filosa* | *Italy* | *Ali Taher* | *Lebanon* |
| *Gian Luca Forni* | *Italy* | *Paul Telfer* | *UK* |
| *Suthat Fucharoen* | *Thailand* | *Elliott Vichinsky* | *USA* |
| *Mahmoud Hajipour* | *Iran* | *Vip Viprakasit* | *Thailand* |
| *Olivier Hermine* | *France* | *Mahmoud Yassin* | *Qatar* |

## Day 1: Friday, September 15, 2017 *(9h training sessions)*

| | |
|---|---|
| 08.00 \| 08.30 | Registrations |
| | PLENARY ROOM (Aula Magna "M. Vignola") |
| 08.30 \| 08.45 | Welcome address<br>*Antonis Kattamis (Greece), Aurelio Maggio (Italy), [illegible]i Taher (Lebanon)* |
| 08.45 \| 09.00 | Greetings from local Authorities |
| 09.00 \| 09.15 | Introduction: Is it time to revisit classification of Thalassemia Syndromes ?<br>*Aurelio Maggio (Italy)* |
| **SESSION I** | THALASSEMIA MAJOR AND ANTIVIRAL TREATMENT<br>Chairpersons: *Antonis Kattamis (Greece), Antonio Piga (Italy)* |
| 09.15 \| 09.30 | Transfusion therapy: what is new with respect to safety and control of iron loading?<br>*Yesim Aydinok (Turkey)* |
| 09.30 \| 09.45 | The future of thalassemia patients without HCV infection: a new history<br>*Vito Di Marco (Italy)* |
| 09.45 \| 10.30 | Interactive Discussion: what is the state of art in transfusion safety and anti-viral treatment of Thalassemia Syndromes worldwide ? Comparing experiences from France, India, Iran, Italy, Saudi Arabia: *Caterina Borgna Pignatti (Italy), Mahmoud Hajipour (Iran), Olivier Hermine (France), Farrukh Shah (KSA), Alok Srivastava (India)* |
| 10.30 \| 10.45 | Discussion |
| 10.45 \| 11.00 | Coffee Break |
| **SESSION II** | THALASSEMIA INTERMEDIA<br>Chairpersons: *Caterina Borgna Pignatti (Italy), Vip Viprakasit (Thailand)* |

11.00 | 11.20 Thalassemia Intermedia: is disease morbidity as we know it today less severe than Thalassemia Major ?
*Ali Taher (Lebanon)*

11.20 | 11.40 Hypercoagulable state in thalassemia
*Eliezer Rachmilewitz (Israel)*

11.40 | 12:00 General insights and current management of Thalassemia Intermedia
*Maria Domenica Cappellini (Italy)*

12.00 | 12.40 Interactive Discussion: what is the state of art in Thalassemia Intermedia management worldwide ? Comparing experiences from Iran, Italy, Malaysia, Qatar:
*Ibrahim Hishamshah (Malaysia), Mehran Karimi (Iran), Paolo Ricchi (Italy), Mahamoud Yassin (Qatar)*

12.40 | 13.00 Discussion

13.00 | 14.00 Light Lunch

## SESSION III

THE NEW ERA OF CHELATION TREATMENT
Chairpersons: *Adriana Ceci (Italy), Alan Cohen (USA)*

14.00 | 14.15 How the era of the new chelators is changing prognosis of Thalassemia Syndromes
*John Porter (UK)*

14.15 | 14.30 Effectiveness and safety of 10 different regimens for controlling iron overloading in Thalassemia Major
*Aurelio Maggio (Italy)*

14.30 | 14.45 Iron overload and Chelation Therapy in Thalassemia Intermedia
*Ali Taher (Lebanon)*

14.45 | 15.30 Interactive Discussion: what is the state of art in chelation management of Thalassemia Syndromes worldwide ? Comparing experiences from Italy, Kuwait, Oman, Pakistan:
*Kunle Adekile (Kuwait), Shahina Daar (Oman), Aldo Filosa (Italy), Saqib Hussein Ansari (Pakistan)*

15.30 | 15.45 Discussion

## SESSION IV

## HIGHLIGHTS IN MANAGEMENT OF THALASSEMIA SYNDROMES IN EASTERN COUNTRIES

Chairpersons: *Marie-Charlotte Bouesseau (Switzerland), Suthat Fucharoen (Thailand)*

**15.45 | 16.05** Management of Thalassemia Syndromes in Egypt: what has been changing during the last 10 years?
*Amal El-Beshlawy (Egypt)*

**16.05 | 16.25** Current management of Thalassemia Syndromes in Thailand: past, present and future
*Vip Viprakasit (Thailand)*

**16.25 | 16.45** Discussion

## SESSION V

## MRI AND CURRENT MANAGEMENT OF THALASSEMIA SYNDROMES

Chairpersons: *Gian Luca Forni (Italy), Paul Telfer (UK)*

**16.45 | 17.05** The impact of MRI in changing prognosis of Thalassemia Major
*Tim St Pierre (Australia)*

**17.05 | 17.25** The MIOT network: an Italian model for management of Thalassemia Syndromes
*Alessia Pepe (Italy)*

**17.25 | 18.15** Interactive Discussion: what is the state of art in MRI facilities worldwide?
Comparing experiences from Egypt, France, India, Saudi Arabia and Thailand:
*Amal El-Beshlawy (Egypt), Olivier Hermine (France), Alok Srivastava (India), Farrukh Shah (KSA), Vip Viprakasit (Thailand)*

**18:15 | 18.30** Discussion

## SESSION VI

## NOVEL STRATEGIES FOR THE TREATMENT OF THALASSEMIA SYNDROMES

Chairpersons: *Paolo Moi (Italy), Ali Taher (Lebanon)*

18.30 | 18.50 Highlights on gene therapy in haemoglobinopathies
*Marina Cavazzana (France)*

18:50 | 19.10 New pharmacological approches for increasing hemoglobin levels in Thalassemia Syndromes
*Antonio Piga (Italy)*

19.10 | 19.30 Conclusions
*Aurelio Maggio (Italy)*

19.30 | 19.45 Hepcidin and iron overload (*NO CME*)
Sponsored talk by **La Jolla Pharmaceutical**
*Lakhmir S. Chawla (US)*

## Day 2: Saturday, September 16, 2017 *(4h15 training sessions)*

### SESSION VII

(Simultaneous sessions)
Panel discussion on RECOMMENDATIONS FOR INITIAL EVALUATION AND STAGING ASSESSMENT OF THALASSEMIA SYNDROMES

08.30 | 10.30 PANEL I (Meeting Room: Aula Fici)

Chairpersons: *Alan Cohen (US), Antonis Kattamis (Greece)*

Discussants: *Marie-Charlotte Bouesseau; Marina Cavazzana, Gianluca Forni, Suthat Fucharoen, Olivier Hermine, Ansari Saqib Hussain, Mehran Karimi, Antonio Piga, John Porter, Paolo Ricchi, Farrukh Shah, Alok Srivatsava, Paul Telfer, Elliott Vichinsky, Vip Viprakasit*

08.30 | 10.30 PANEL II (Meeting Room: Biblioteca – Ospedale "V. Cervello")

Chairpersons: *Amal El-Beshlawy (Egypt), Ali Taher (Lebanon)*

Discussants: *Kunle Adekile, Caterina Borgna Pignatti, Maria Domenica Cappellini, Adriana Ceci, Shahina Daar, Vito Di Marco, Aldo Filosa, Mahmoud Hajipour, Ibrahim Hishamshah, Aurelio Maggio, Alessia Pepe, Eliezer Rachmilewitz, Tim St Pierre, Mahmoud Yassin*

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|---|---|
| 10.30 \| 10.45 | Coffee Break |
| | PLENARY ROOM (AULA MAGNA "M. VIGNOLA")<br>CHAIRPERSONS: *Aurelio Maggio (Italy), Ali Taher (Lebanon), Paul Telfer (UK), Elliott Vichinsky (US)* |
| 10.45 \| 11.15 | **Presentation of Panel I** - Recommendations for initial evaluation and staging assessment of Thalassemia Syndromes *Alan Cohen (US), Antonis Kattamis (Greece)* |
| 11.15 \| 11.45 | **Presentation of Panel II** - Recommendations for initial evaluation and staging assessment of Thalassemia Syndromes<br>*Amal El-Beshlawy (Egypt), Ali Taher (Lebanon)* |
| 11.45 \| 12.30 | Discussion for general consensus on Presentations of Panel I and II |
| 12.30 \| 13.00 | Final proposal and future strategy<br>*Aurelio Maggio (Italy)* |
| 13.00 \| 13.15 | CME questionnaire |
| 13.15 \| 13.30 | Closing remarks<br>*Aurelio Maggio (Italy)* |
| 13.30 \| 14.30 | Light Lunch |
| 14.30 \| 16.00 | **Poster Session I** on<br>THALASSEMIA MAJOR AND ANTIVIRAL TREATMENT, THALASSEMIA INTERMEDIA AND THE NEW ERA OF CHELATION TREATMENT |
| 16.00 \| 17.30 | **Poster Session II** on<br>HIGHLIGHTS IN MANAGEMENT OF THALASSEMIA SYNDROMES IN EASTERN COUNTRIES, MRI AND CURRENT MANAGEMENT OF THALASSEMIA SYNDROMES AND NOVEL STRATEGIES FOR THE TREATMENT OF THALASSEMIA SYNDROMES |
| 17.30 \| 17.45 | Conclusions<br>*Aurelio Maggio (Italy)* |

NO CME

**If consensus is reached we will aim to submit our results to a leading international journal.**


## Ackowledgments

*We thank Foundation Franco and Piera Cutino for the support to the organization of the course.*

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## *MEETING VENUE*

*CAMPUS OF HEMATOLOGY "Franco e Piera Cutino"*
*A.O.R. "Villa Sofia - V. Cervello" - Palermo (Italy)*

## *C.M.E. CONTINUING MEDICAL EDUCATION*

Collage S.p.A. (Provider n. 309) has included the Meeting in the Educational Plan 2017.
C.M.E ref. :309-197251.

The Congress will be suited for Physicians (Hematologists, Transfusiologists, Pediatricians, Radiologists, Biotecnologists), Pharmacologists, Biologists.

and provides 13 C.M.E. credits.

*In order to obtain C.M.E. credits, participants must:*

- *attend the 90% of the Meeting (15 and 16 September)*
- *Fill-in the CME evaluation questionnaire (credits will be granted to those who will answer 75% correctly)*
- *belong to the credited Medical Profession and Specializations related to this Meeting*
- *Submit the required documentation, sign in and sign out at the registration desk at the beginning/end of the Congress.*

## *C.M.E. CERTIFICATION*

*The certificate of attendance with the number of C.M.E. assigned credits can be downloaded after 91 days from the date of the Meeting directly through the website www.collage-spa.it/sezione congressi ecm / corsi ecm / select the year and the title of the Event/digit your fiscal code and download your certification.*

## *CERTIFICATE OF ATTENDANCE*

*Certificate of attendance will be issued at the registration desk at the end of the Meeting.*

## *REGISTRATION FEE € 400,00 (22% VAT not included)*

*It includes: attendance at the scientific sessions, coffee breaks and buffet lunches as indicated in the scientific program, congress badge, congress kit. Please confirm your participation to the Organizing Secretariat by registering online at **www.collage-spa.it/congressi-corsi/** by July 20th, 2017.*

## *CALL FOR ABSTRACTS (deadline 15 July, 2017)*

*Poster Sessions will be featured on 16 September from 14.30 to 17.30 to ensure delegates are given the opportunity to review as many abstracts as possible.*
*Please visit **www.collage-spa.it/congressi-corsi/** for abstracts guidelines and submission.*

## *PAYMENTS*

*Payments will be possible exclusively by bank transfer to*
*COMITATO INTERNATIONAL GROUP FOR THALASSEMIA account:*
*IBAN: IT37 E033 5901 6001 0000 0151 884*
*BIC: BCITITMX*
*Please note that your registration will only be valid when full payment is received by the administrative office. Payment done by bank transfer must be certified with the copy of the receipt of the bank to be uploaded in the registration form or sent to e-mail to giusy.ventura@collage-spa.it*

## *OFFICIAL LANGUAGE*

*The official language of the Meeting will be English. No simultaneous translation will be provided.*

## *DEDICATED WEBSITE*

*www.iwgthalassemia.it*

CME Provider and Organizing Secretariat

COLLAGE S.p.A.
Via U. Giordano, 37/A - 90144 Palermo - Italy - Tel. +39 091 6867.401 - Fax +39 091 9889354
e-mail: giusy.ventura@collage-spa.it - web: www.collage-spa.it