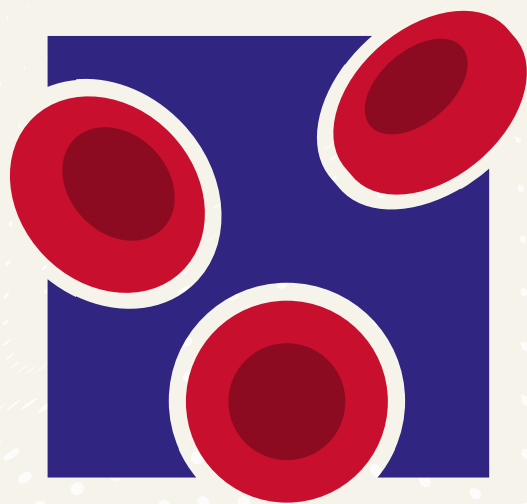




1ST PAN AMERICAN CONFERENCE

THALASSAEMIA
HAEMOGLOBIN
2ND RAIN SUMMIT

AND OTHER
DISORDERS &

11 - 13 JULY
WASHINGTON D.C., USA



THALASSAEMIA
INTERNATIONAL
FEDERATION

PROGRAMME



Organised by:



THALASSAEMIA
INTERNATIONAL
FEDERATION

In collaboration with:



Cooley's Anemia Foundation
70 Years of Leading the Fight Against Thalassemia

Supported by:



PAN AMERICAN NETWORK
FOR HAEMOGLOBIN DISORDERS

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The Thalassaemia International Federation is accredited by the American Association of Continuing Medical Education® to provide continuing medical education for physicians. The Accreditation Review Committee designates this educational activity for a maximum of 19 category I credits in the Association's Credit Designation. Each physician must claim only those credits that he/she actually spent in the educational activity.

It is the policy of the American Association of Continuing Medical Education® to ensure balance, independence, objectivity, and scientific rigor in all its sponsored educational programs. All faculty participating in continuing medical education activities sponsored by Thalassaemia International Federation are required to disclose to the program audience any real or apparent conflict of interest related to the content of their presentations. All faculty are also required to disclose any discussions of unlabeled/unapproved uses of drugs or devices.



HIGHLIGHTS

- Advances in Thalassaemia and Sickle Cell Disease Management
- Gene and Cell-Based Therapies: Future Prospects
- Multidisciplinary Care Models for Haemoglobinopathies
- Health Equity and Addressing Unmet Needs
- Capacity Building for Patients
- Regional and Global Policy Initiatives for Improved Access to Care
- **RAIN Summit:** Regional Collaboration for Sustainable Change in Rare Anaemias



INTRODUCTION

The 1st Pan American Conference on Thalassaemia and Other Haemoglobin Disorders, organized by the Thalassaemia International Federation (TIF) in collaboration with the Cooley's Anemia Foundation (CAF) and supported by the Pan American Network for Haemoglobin Disorders (PANHD)*, marks a pivotal gathering designed to strengthen education, foster collaboration, and build regional capacity in the management of haemoglobin disorders across the Americas. Scheduled to take place from July 11–13, 2025, at the Hyatt Regency Crystal City in Washington, D.C., the conference will convene healthcare professionals, patients, caregivers, and advocacy groups to promote knowledge exchange, enhance clinical practices, and support the development of sustainable care models tailored to the needs of affected communities in the region.

The conference will feature **two parallel programmes:**

A **Scientific Programme** designed for healthcare professionals focusing on multidisciplinary care, new treatment approaches, innovative therapies, and emerging challenges in the field.

A **Patient and Parent Programme** aimed at empowering, educating, and connecting patient communities across the Americas to strengthen advocacy efforts and improve healthcare access.

In conjunction with the main conference, the **2nd Rare Anaemia International Network (RAIN) Summit** will serve as a dedicated platform to foster collaboration, share best practices, and strengthen regional networks among national alliances focused on rare anaemias. This dual-event structure underscores the commitment to addressing unmet patient needs, promoting equitable access to care, and enhancing the quality of life for affected individuals and their families.

OBJECTIVES

- To master fundamentals of clinical management of haemoglobin disorders
- To enhance knowledge and awareness
- To foster collaboration and networking
- To address unmet patient needs
- To strengthen national and regional strategies
- To amplify patient advocacy and engagement
- To celebrate achievements and inspire future action

**PANHD Countries: Argentina, Brazil, Canada, Trinidad & Tobago, and United States of America*



ORGANISING COMMITTEE

ENGLEZOS, Panos	Cyprus	President , Thalassaemia International Federation
ELEFThERIOU, Androulla	Cyprus	Executive Director , Thalassaemia International Federation
COLASANTI, Ralph	United States	National President , Cooley's Anemia Foundation
BUTLER, Craig	United States	National Executive Director , Cooley's Anemia Foundation

SCIENTIFIC ADVISORY COMMITTEE *

AL-SAMKARI, Hanny	United	Classical Haematologist and Clinical Investigator , The Peggy S. Blitz Endowed Chair in Haematology/Oncology; Co-Director , Hereditary Haemorrhagic Telangiectasia Centre, Massachusetts General Hospital; Associate Professor of Medicine, Harvard Medical School
AMID, Ali	Canada	Director , Provincial Paediatric Haemoglobinopathy Program, BC Children's Hospital; University of British Columbia, Vancouver
ANGASTINIOTIS, Michael	Cyprus	Medical Advisor , Thalassaemia International Federation (TIF)
BALDANZI, Giorgio	Brazil	Haematologist , Haematology and Haemotherapy Center of Paraná (HEMEPAR), Curitiba, Paraná
COATES, Thomas	United States	Professor of Paediatrics and Pathology, Section Head , Haematology, Cancer and Blood Disease Institute, University of Southern California Keck School of Medicine; Children's Hospital Los Angeles
COHEN, Alan	United States	Haematologist , Division of haematology, Children's Hospital of Philadelphia
CORRONS, Joan-Lluis Vives	Spain	Emeritus Professor , University of Barcelona; Leukaemia Research Institute Josep Carreras; Clinical Centre for Ambulatory Medicine, Ektacytometry Unit, Barcelona, Catalonia
DARRIGO JÚNIOR, Luiz Guilherme	Brazil	Paediatric Haematology and Oncology , Department of Paediatrics, Ribeirão Preto School of Medicine, University of São Paulo
FERNANDES, Juliano de Lara	Brazil	Cardiovascular Imaging Center, José Michel Kalaf Research Institute, Campinas, São Paulo
FUNG, Ellen B.	United States	Adjunct Professor , Division of Hematology, Department of Pediatrics, UCSF; Director, Bone Density Clinic; Co-Director, Summer Student Research Program, UCSF Benioff Children's Hospital Oakland
GRACE, Rachael F.	United States	Attending Physician , Paediatric Haematology, Boston Children's Hospital; Associate Professor, Harvard Medical School, Boston, Massachusetts
GREENE, Camille	Trinidad & Tobago	General Pediatric Consultant , Eric Williams Medical Sciences Complex; Co-Consultant , Pediatric Hematology; Associate Clinical Instructor, Child Health Unit, University of the West Indies; Technical Medical Director , Society for Inherited & Severe Blood Disorders Trinidad and Tobago (SISBDTT); Board Member , Children's Life Fund Authority (CLFA)
HOBSON, Florelle	Saint Kitts & Nevis	Medical Chief of Staff , Alexandra Hospital; Ministry of Health, Gender Affairs and Social Empowerment (NIA), Government Road, Charlestown, Nevis
KANTER, Julie	United States	Director , Adult Sickle Cell Disease Program; Associate Professor , Medicine and Pediatrics, University of Alabama at Birmingham

*listed in alphabetical order based on last name



KUO, Kevin H.M	Canada	Associate Professor , Division of Hematology, Department of Medicine, Faculty of Medicine, University of Toronto; Associate Professor , Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto
KWIATKOWSKI, Janet	United States	Professor of Pediatrics , Perelman School of Medicine, University of Pennsylvania; Director, Thalassemia Center, Children's Hospital of Philadelphia
LEELAH, Niall	Trinidad & Tobago	Chairman , Hospital Transfusion Committee, General Hospital Port of Spain; Member, Trinidad and Tobago Society for Haematology and Blood Transfusion (TTSBHT)
LOGGETTO, Sandra	Brazil	Paediatric Haematologist , Haematology Department, Sabará Children's Hospital, São Paulo, Brazil; Paediatric Haematologist , São Paulo Blood Bank, GSH Group
MERKELEY, Hayley	Canada	Clinical Haematologist , Specialist in Red Blood Cell Disorders; Clinical Assistant Professor , University of British Columbia, Vancouver, British Columbia
MOHANDAS, Narla	United States	Distinguished Scientist , Head, Laboratory of Red Cell Physiology, New York Blood Center Enterprises; Vice President , American Society of Hematology, New York
MUSALLAM, Khaled	UAE	Group Chief Research Officer , Burjeel Holdings; Director, Thalassemia & Sickle Cell Center; Founding Director, Centre for Research on Rare Blood Disorders (CR-RBD), Burjeel Medical City, Abu Dhabi, UAE; Adjunct Professor , Khalifa University, Abu Dhabi & Weill Cornell Medicine, New York
ODAME, Issac	Canada	Professor , Department of Paediatrics, University of Toronto; Section Head, Division of Haematology/Oncology; Medical Director , Global Sickle Cell Disease Network, Centre for Global Child Health, The Hospital for Sick Children, Toronto, Ontario, Canada
RIVELLA, Stefano	United States	Professor of Paediatrics , Children's Hospital of Philadelphia; Leader, RNA Gene Therapeutics Group, Penn Institute for RNA Innovation; Scientific Director , CuRED, Philadelphia
SAYANI, Farzana	Canada	Associate Professor of Clinical Medicine (Haematology-Oncology) ; Director , Penn Comprehensive Adult Thalassemia Program; Director , Penn Comprehensive Sickle Cell Program, University of Pennsylvania, Philadelphia
VERISSIMO, Monica	Brazil	Head , Haematology Department, Blood Bank and Thalassemia Program, Boldrini Children's Center, Campinas, São Paulo
WALTER, Mark	United States	Director , Blood & Marrow Transplant Program, UCSF Benioff Children's Hospital Oakland; Chief , Haematology Division; Professor , Pediatrics/Haematology, University of California, San Francisco, Oakland
WOOD, John	United States	Professor of Pediatrics , Radiology, and Bioengineering, University of Southern California; Director , Cardiovascular Imaging, Children's Hospital Los Angeles

ABSTRACT REVIEW COMMITTEE *

AMID, Ali	Canada	Director , Provincial Paediatric Haemoglobinopathy Program, BC Children's Hospital; University of British Columbia, Vancouver
ANGASTINIOTIS, Michael	Cyprus	Medical Advisor , Thalassemia International Federation (TIF)
CAPPELLINI, Maria Domenica	Italy	Professor of Internal Medicine , University of Milan; Chief, Rare Diseases Centre, Fondazione IRCCS Policlinico Hospital, Milan

* listed in alphabetical order based on last name



COATES, Thomas	United States	Professor of Paediatrics and Pathology , Section Head, Haematology, Cancer and Blood Disease Institute, University of Southern California Keck School of Medicine; Children's Hospital Los Angeles
GRACE, Rachael F.	United States	Attending Physician , Paediatric Haematology, Boston Children's Hospital; Associate Professor, Harvard Medical School, Boston, Massachusetts
JACOBSON, David A.	United States	Professor of Paediatrics , Chief, Division of Blood and Marrow Transplantation, Children's National Hospital; George Washington University School of Medicine and Health Sciences, Washington, DC
KUO, Kevin H. M.	Canada	Associate Professor , Division of Haematology, Department of Medicine, University of Toronto; Associate Professor , Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto
KWIATKOWSKI, Janet	United States	Professor of Paediatrics , Perelman School of Medicine, University of Pennsylvania; Director , Thalassaemia Centre, Children's Hospital of Philadelphia
RIVELLA, Stefano	United States	Professor of Paediatrics , Children's Hospital of Philadelphia; Leader, RNA Gene Therapeutics Group, Penn Institute for RNA Innovation; Scientific Director , CuRED, Philadelphia
SAYANI, Farzana	United States	Associate Professor of Clinical Medicine (Haematology-Oncology) ; Director , Penn Comprehensive Adult Thalassaemia Program; Director , Penn Comprehensive Sickle Cell Program, University of Pennsylvania, Philadelphia

PATIENTS/ PARENTS ADVISORY COMMITTEE *

BONGIORNO, Miguel Angel	Argentina	President , Argentinian Thalassaemia Association (ATA)
BRATHWAITE, Jason	Trinidad & Tobago	Member , Society for Inherited & Severe Blood Disorders
BUTLER, Craig	United States	National Executive Director , Cooley's Anemia Foundation
CALABRIA, Bessie	Canada	President , Thalassaemia Foundation of Canada; Board Member , Thalassaemia International Federation
DHILLON, Sharni	Canada	Member , Thalassaemia Foundation of Canada; Board Member, Thalassaemia International Federation
DI ROBERTO, Isabely	Brazil	Member , Brazilian Thalassaemia Association (ABRSTA)
FICARRA, Robert	United States	Board Member , Cooley's Anemia Foundation; Former Board Member, Thalassaemia International Federation
GIOSEFFI, Janaína Rosenberg	Brazil	Member , Brazilian Thalassaemia Association (ABRSTA)
HADJIDEMETRIOU, Maria	United States	Board Member , Cooley's Anemia Foundation; Board Member, Thalassaemia International Federation, New York
MAHARAJ, Shenelle	Trinidad & Tobago	Member , Society for Inherited & Severe Blood Disorders
SAWH, Radhika	United States	Board Member , Cooley's Anemia Foundation



FACULTY *

AL-SAMKARI, Hanny	United States	Classical Haematologist and Clinical Investigator , The Peggy S. Blitz Endowed Chair in Haematology/Oncology; Co-Director , Hereditary Haemorrhagic Telangiectasia Centre, Massachusetts General Hospital; Associate Professor of Medicine , Harvard Medical School
AMID, Ali	Canada	Director , Provincial Paediatric Haemoglobinopathy Program, BC Children's Hospital; University of British Columbia, Vancouver
ANSELM, Hennis	United States	Director , Department of Noncommunicable Diseases and Mental Health, PAHO/WHO, Washington, DC
BADALAMENTI, NinaMaria	United States	News Producer , Chicago, Illinois
BADAWY, Sherif	United States	Director , Comprehensive Adult and Paediatric Thalassaemia Program, Ann & Robert H. Lurie Children's Hospital of Chicago; Associate Professor of Paediatrics , Northwestern University Feinberg School of Medicine
BASTOS, Andre Luiz Rodrigues	Brazil	Member , HOMPE
BLOOMBERG, Maya	United States	Classical Haematology Nurse Practitioner , Sylvester Comprehensive Cancer Centre, Jackson Memorial Hospital
BONGIORNO, Lucio Miguel	Argentina	Member , Argentinian Thalassaemia Association (ATA)
BRATHWAITE, Jason	Trinidad & Tobago	Member , Society for Inherited & Severe Blood Disorders
CALABRIA, Bessie	Canada	President , Thalassaemia Foundation of Canada; Board Member, Thalassaemia International Federation
CANNON, Lily	Cyprus	Deputy Director , Thalassaemia International Federation
CAPPELLINI, Maria Domenica	Italy	Professor of Internal Medicine , University of Milan; Chief, Rare Diseases Centre, Fondazione IRCCS Policlinico Hospital, Milan
CHENG, Aaron	United States	Hematology Fellow , Hospital of the University of Pennsylvania
CILLO, Maria Florencia	Argentina	Member , Argentinian Thalassaemia Association (ATA)
COATES, Thomas	United States	Professor of Paediatrics and Pathology , Section Head, Haematology, Cancer and Blood Disease Institute, University of Southern California Keck School of Medicine; Children's Hospital Los Angeles
DI ROBERTO, Isabely	Brazil	Member , Brazilian Thalassaemia Association (ABRSTA)
DURST, Kathleen	United States	Social Worker , Cooley's Anemia Foundation, New York
FARMAKIS, Dimitrios	Greece	Professor, Consultant Cardiologist , National and Kapodistrian University of Athens, Athens, Greece; Medical Advisor , Thalassaemia International Federation
FICARRA, Robert	United States	Board Member , Cooley's Anemia Foundation; Former Board Member, Thalassaemia International Federation
FOLLETT, Addassa	United Kingdom	Member , UK Sickle Cell Society
GRACE, Rachael F.	United States	Attending Physician , Paediatric Haematology, Boston Children's Hospital; Associate Professor , Harvard Medical School, Boston, Massachusetts
HADJIDEMETRIOU, Maria	United States	Board Member , Cooley's Anemia Foundation; Board Member , Thalassaemia International Federation, New York
JACOBSON, David A.	United States	Professor of Paediatrics , Chief, Division of Blood and Marrow Transplantation, Children's National Hospital; George Washington University School of Medicine and Health Sciences, Washington, DC

* listed in alphabetical order based on last name



KUO, Kevin H. M.	Canada	Associate Professor , Division of Haematology, Department of Medicine, University of Toronto; Associate Professor , Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto
KWIATKOWSKI, Janet	United States	Professor of Paediatrics , Perelman School of Medicine, University of Pennsylvania; Director , Thalassaemia Centre, Children's Hospital of Philadelphia, USA
LAL, Ashutosh	United States	Professor of Clinical Paediatrics , UCSF School of Medicine; Comprehensive Thalassaemia Centre & Iron Disorders Program, UCSF Benioff Children's Hospital, Oakland, USA
LANDER, Carl	United Kingdom	International Liaison , Pyruvate Kinase Deficiency International Alliance (PKDIA)
LOGGETTO, Sandra	Brazil	Paediatric Haematologist , Sabará Children's Hospital; São Paulo Blood Bank, GSH Group
MAHARAJ, Shenelle	Trinidad and Tobago	Member , Society for Inherited & Severe Blood Disorders
MALINOWSKI, Kinga	Canada	Maternal-Fetal Medicine Physician , Department of Obstetrics and Gynaecology, McMaster University Medical Centre & Mount Sinai Hospital, University of Toronto; Professor, Department of Health Research Methods, Evidence & Impact, McMaster University
MANNINO, Rob	United States	Member , Cooley's Anemia Foundation
MATTHIES, Stephanie	United States	Nurse , APRN, PNP-PC, Department of Haematology, Oncology & Stem Cell Transplant, Ann & Robert H. Lurie Children's Hospital of Chicago
MOHANDAS, Narla	United States	Distinguished Scientist , Head, Laboratory of Red Cell Physiology, New York Blood Centre Enterprises; Vice President , American Society of Haematology, New York
MUSALLAM, Khaled	United Arab Emirates	Group Chief Research Officer , Burjeel Holdings; Director, Thalassaemia & Sickle Cell Center; Founding Director , Centre for Research on Rare Blood Disorders (CR-RBD), Burjeel Medical City, Abu Dhabi, UAE; Adjunct Professor , Khalifa University, Abu Dhabi & Weill Cornell Medicine, New York
PALHARINI, Rafaela Limão	Brazil	Member , Brazilian Thalassaemia Association (ABRSTA)
PESLAK, Scott A.	United States	Assistant Professor of Medicine , Division of Haematology/Oncology, University of Pennsylvania Perelman School of Medicine; Director , Penn Comprehensive Adult Thalassaemia Program
RINALDI, Aliya	United States	Member , Cooley's Anemia Foundation
RIVELLA, Stefano	United States	Professor of Paediatrics , Children's Hospital of Philadelphia; Leader, RNA Gene Therapeutics Group, Penn Institute for RNA Innovation; Scientific Director, CuRED, Philadelphia
SAWH, Radhika	United States	Board Member , Cooley's Anemia Foundation
SCHRYVER, Tamara	United States	Co-Founder and Co-Chair , Pyruvate Kinase Deficiency International Alliance
STEAGALL, Dina	Brazil	Vice President , Brazilian Thalassaemia Association (ABRSTA)
TELFER, Paul	United Kingdom	Honorary Consultant Haematologist and Paediatric Haematologist , Barts Health NHS Trust; Clinical Director, East London and Essex Clinical Haemoglobinopathy Network – Sickle Cell Disease & Thalassaemia
TRAXLER, Elizabeth	United States	Assistant Professor of Medicine , Division of Haematology/Oncology, University of Pennsylvania Perelman School of Medicine
WOOD, John	United States	Professor of Pediatrics , Radiology, and Bioengineering, University of Southern California; Director of Cardiovascular Program , Children's Hospital Los Angeles



SCIENTIFIC PROGRAMME*

FRIDAY, 11 JULY 2025

JOINT PROGRAMME

HALL: REGENCY EF

15:00 - 15:30 OPENING CEREMONY AND WELCOME ADDRESSES *Hall: Regency EF*

Introduction by Mr Robert Ficarra and Prof. Dimitrios Farmakis

Welcome Address by the:

- President of Thalassaemia International Federation, Dr Panos Englezos
- National President of Cooley's Anemia Foundation, Mr Ralph Colasanti
- Former President of the American Hematology Society (ASH), Dr Narla Mohandas

Awards Ceremony

15:30 - 17:00 SESSION 1. KEYNOTE SESSION *Hall: Regency EF* Chairpersons: Bessie Calabria & Ralph Colasanti

15:30 - 15:40	The Value of Regional Networks - TIF's Perspective	Dimitrios Farmakis
15:40 - 15:55	The Contribution of Haemoglobin Disorders to the Regional Disease Burden - TIF's Perspective	Dimitrios Farmakis
15:55 - 16:20	Bridging Gaps and Addressing Challenges in the Care of Haemoglobin Disorders: Past - Present - Future	Hennis Anselm
16:20 - 16:50	Patient Voices - Personal Journeys Across the Americas: My Truth, My Story • Testimonials from: USA, Canada, Brazil, Argentina, and Trinidad & Tobago	Rob Mannino – USA Bessie Calabria – Canada Isabely Di Roberto – Brazil Lucio M. Bongiorno – Argentina Jason Brathwaite - Trinidad & Tobago
16:50 - 16:56	A Unique Journey of Love: Embracing the Rewards and Challenges of Adopting Children with Thalassaemia	Michelle Campbell
16:56 - 17:00	The Work and Contribution of TIF (Video)	

17:00 - 19:00 ORAL ABSTRACT PRESENTATIONS * *Hall: Regency AB* Chairpersons: Ali Amid & John Wood

Real-world safety profile of twice-daily deferiprone for iron overload in us patients with thalassaemia, sickle cell disease or other anaemias THEME: IRON OVERLOAD & MANAGEMENT	Thomas Coates
Exposure-response of daily versus twice daily deferasirox dosing in patients with transfusion dependent thalassaemia THEME: IRON OVERLOAD & MANAGEMENT	Ashutosh Lal
Weaker Bones Relative to Body Size in Patients with Thalassaemia Compared to Healthy Controls THEME: BONE HEALTH	Ellen Fung
Activism-based commentary on communication breakdown regarding transfusion policy at MUHC THEME: PSYCHO-SOCIAL ISSUES	Julia Scala
Decreased lean mass is associated with reduced muscle function in patients with Thalassaemia THEME: LIFESTYLE ISSUES	Ellen Fung
The Greek-American diaspora: a patient population in need of 2 increased β -thalassaemia carrier status education and screening THEME: EPIDEMIOLOGY	Zissis Chroneos
Improvement of Symptomatic Anemia with Luspatercept in a patient having Heterozygous STEPA3/TSAP6 mutation and Beta-Thalassaemia trait THEME: NEW ADVANCES IN TREATMENT	Akhila Vadivelan
Hematopoietic Stem Cell Transplantation (HCT) for symptomatic non-transfusion dependant Congenital Dyserythropoietic Anemia II (CDAlI) THEME: HAEMATOPOIETIC STEM CELL TRANSPLANTATION (HSCT)	Elizabeth Yang

*Access restricted to specific registration categories



SATURDAY, 12 JULY 2025

HALL: REGENCY AB

07:00 - 08:00 CONTINENTAL BREAKFAST - Hall: Regency CD

08:00 - 10:00 **SESSION 2. STANDARD OF CARE FOR HAEMOGLOBIN DISORDERS – THALASSAEMIA**
Chairpersons: Sandra Loggetto & John Wood

08:00 - 08:25	Blood Transfusion Management: Ensuring Safety, Efficacy, and Long-Term Patient Well-Being	Thomas Coates
08:25 - 08:45	Iron Overload and Monitoring - Strategies for effective chelation and long-term patient care	Paul Telfer
08:45 - 09:05	Systemic Complications in Thalassaemia: Endocrine Disorders, Liver Disease, Fertility Challenges	Maria Domenica Cappellini
09:05 - 09:25	Cardiac Health	John Wood
09:25 - 09:45	Enhancing Care for α -Thalassaemia: Recognizing Challenges and Realizing Opportunities	Ali Amid
09:45 - 10:00	Panel Discussion and Q&A: Expert insights and audience engagement on comprehensive disease management.	

10:00 - 10:30 COFFEE BREAK

10:30 - 12:00 **SESSION 3. THE REVOLUTION OF NEW ADVANCES – DOES SCIENCE INDEED SERVE THE PATIENT?**
Chairpersons: Janet Kwiatkowski & Stefano Rivella

10:30 - 10:55	Current and Emerging Drug Therapies for Haemoglobin Disorders	Kevin H.M Kuo
10:55 - 11:20	Gene-Based Therapies for Haemoglobin Disorders: Progress and Future Prospects	Stefano Rivella
11:20 - 11:45	Haematopoietic Stem Cell Transplantation (HSCT): Current Experience with a Proven Curative Approach for Haemoglobin Disorders	David A. Jacobsohn
11:45 - 12:00	Panel Discussion and Q&A	

12:00 - 13:30 LUNCH BREAK

12:00 - 13:30 **SATELLITE SYMPOSIUM - SUPPORTED BY** 

Advancing Thalassaemia Management: Insights into Clinical Data and Disease Burden

Sarah Gheuens
Khaled M. Musallam
Kevin H.M. Kuo
Maria Domenica Cappellini

13:30 - 15:00 **SESSION 4. PROVIDING OPTIMUM CARE TO PATIENTS WITH HAEMOGLOBIN DISORDERS: CONSIDERATIONS BEYOND THE TREATING PHYSICIAN**
Chairpersons: Thomas Coates & Maria Domenica Cappellini

13:30 - 13:50	Navigating the Transition from Paediatric to Adult Care	Khaled Musallam
13:50 - 14:10	Challenges in Managing Thalassaemia and other Haemoglobin Disorders in Multi-cultural Setting	Ashutosh Lal
14:10 - 14:30	The Role of Nursing in the Care for Haemoglobin Disorders	Maya Bloomberg
14:30 - 14:50	The Contribution of the Social Worker in the Care of Haemoglobin Disorders	Kathleen Durst
14:50 - 15:00	Panel Discussion and Q&A	

15:00 - 15:30 COFFEE BREAK



15:30 - 16:45 SESSION 5. STRENGTHENING NATIONAL STRATEGIES FOR THE CONTROL OF HAEMOGLOBIN DISORDERS

Chairpersons: Paul Telfer & Ashutosh Lal

15:30 - 15:50	The Role of National Registries in Improving Patient Care and Disease Management	Maria Domenica Cappellini
15:50 - 16:10	National Prevention Programme and Neonatal Screening – the Keys to the More Effective Control of Haemoglobin Disorders	Paul Telfer
16:10 - 16:30	The Role of Reference Centres and Regional Networking in Enhancing Patient Care	Janet Kwiatkowski
16:30 - 16:45	Panel Discussion & Q&A	

16:45 - 18:00 SESSION 6. FUTURE DIRECTIONS IN HAEMOGLOBINOPATHY CARE

Chairpersons: Hanny Al-Samkari & David A. Jacobsohn

16:45 - 17:10	Artificial Intelligence, Telemedicine & Digital Health in the Service of Haemoglobin Disorders	Hanny Al-Samkari
17:10 - 17:35	Addressing Challenges in Accessibility, Availability, and Affordability of New Advances across the region	Lily Cannon
17:35 - 18:00	Panel Discussion and Q&A	

17:30 RECEPTION HOSTED BY  Society of America Foundation**SUNDAY, 13 JULY 2025****HALL: REGENCY AB****07:00 - 08:00 CONTINENTAL BREAKFAST - Hall: Regency CD****08:00 - 10:00 SESSION 7. CASE PRESENTATIONS**

Chairpersons: Paul Telfer & Scott Peslak

Progressive Anaemia and Splenomegaly in an Adult with HbE/Beta Thalassemia	Aaron N. Cheng
Moderate Hepatic Iron Overload in Transfusion-Dependent Beta-Thalassemia Children Under 3 Years of Age	Sandra Loggetto
Case presentation on: Dominant Thalassemia, improved by Luspatercept	Thomas Coates
Case presentation on: Management of liver injury in thalassemia	Sherif Badawy & Stephanie Matthies
Case presentation on: Treatment of Cardiac Iron Overload in the Context of Recurrent Infection	Elizabeth Traxler
Late-Onset Transfusion Dependency in Adult with Non-Transfusion Dependent Thalassemia	Sandra Loggetto

10:00 - 10:30 COFFEE BREAK**2nd RARE ANAEMIA INTERNATIONAL NETWORK (RAIN) SUMMIT HALL: REGENCY EF****JOINT PROGRAMME****10:30 - 13:00 SESSION 8. RARE ANAEMIAS: ADVANCING KNOWLEDGE AND ACCESS TO QUALITY CARE**

Chairpersons: Hanny Al-Samkari & Lily Cannon

10:30 - 10:50	Evolving Therapeutic Strategies for Rare Anaemias	Hanny Al-Samkari
10:50 - 11:30	Hearing from the community - Best Practices from: • Carl Lander- PKDIA Foundation (UK) • Andre Luiz Rodrigues Bastos - HEMOPE (Brazil) • Addassa Follett - UK Sickle Cell Society (UK) • Shenelle Maharaj - The Society for Inherited & Severe Blood Disorders T&T Limited – (T&T)	
11:30 - 12:00	Access to Treatment: Knowledge and Education for Rare Anaemias	Rachael F. Grace
12:00 - 12:30	Diagnostic Challenges in Rare Anaemia	Narla Mohandas
12:30 - 13:00	Interactive Discussion: Future actions and activities	Panel Discussion



PATIENTS' PROGRAMME

FRIDAY, 11 JULY 2025

JOINT PROGRAMME

HALL: REGENCY EF

15:00 - 15:30 OPENING CEREMONY AND WELCOME ADDRESSES

Hall: Regency EF

Introduction by Mr Robert Ficarra and Prof. Dimitrios Farmakis

Welcome Address by the:

- President of Thalassaemia International Federation, Dr Panos Englezos
- National President of Cooley's Anemia Foundation, Mr Ralph Colasanti
- Former President of the American Hematology Society (ASH), Dr Narla Mohandas

Awards Ceremony

15:30 - 17:00 SESSION 1. KEYNOTE SESSION

Hall: Regency EF

Chairpersons: Bessie Calabria & Ralph Colasanti

15:30 - 15:40 The Value of Regional Networks - TIF's Perspective

Dimitrios Farmakis

15:40 - 15:55 The Contribution of Haemoglobin Disorders to the Regional Disease Burden - TIF's Perspective

Dimitrios Farmakis

15:55 - 16:20 Bridging Gaps and Addressing Challenges in the Care of Haemoglobin Disorders: Past - Present - Future

Hennis Anselm

16:20 - 16:50 Patient Voices - Personal Journeys Across the Americas: My Truth, My Story

- Testimonials from: USA, Canada, Brazil, Argentina, and Trinidad & Tobago

Rob Mannino – USA

Bessie Calabria – Canada

Isabely Di Roberto – Brazil

Lucio M. Bongiorno – Argentina

Jason Brathwaite - Trinidad & Tobago

16:50 - 16:56 A Unique Journey of Love: Embracing the Rewards and Challenges of Adopting Children with Thalassaemia

Michelle Campbell

16:56 - 17:00 The Work and Contribution of TIF (Video)

17:00 - 18:00 SESSION 2. BUILDING CONNECTIONS: PATIENT PANEL DISCUSSION

Hosts: Kevin H.M Kuo and NinaMaria Badalamenti

A patient panel featuring one representative from each country.
The discussion will be recorded as a podcast episode.

Radhika Sawh

Rafaela Limão Palharini

Maria Florencia Cillo

SATURDAY, 12 JULY 2025

HALL: REGENCY EF

07:00 - 08:00 CONTINENTAL BREAKFAST - Hall: Regency CD

08:00 - 10:00 SESSION 3. MENTAL & SOCIAL WELL-BEING IN THALASSAEMIA: STRENGTHENING EMOTIONAL & COMMUNITY SUPPORT

Chairpersons: Craig Butler & Robert Ficarra

08:00 - 08:20 Coping with Anxiety & Stress: Strategies for Mental Resilience

Kathleen Durst

08:20 - 08:40 Building Confidence & Overcoming Challenges in Daily Life

Bessie Calabria

08:40 - 09:00 How to Talk About Your Condition with Family & Friends

Maria Hadjidemetriou

09:00 - 09:20 Navigating the Transition from Paediatric to Adult Care

Khaled Musallam

09:20 - 10:00 Panel Discussion and Q&A

10:00 - 10:30 COFFEE BREAK



10:30 - 12:00 **SESSION 4. ALIGNING STANDARDS OF CARE WITH INTERNATIONAL GUIDELINES**

Chairpersons: Thomas Coates & Maria Domenica Cappellini

- | | | |
|---------------|---|---------------------------|
| 10:30 - 10:55 | Management of Transfusion-Dependent β -Thalassaemia: Key Messages | Paul Telfer |
| 10:55 - 11:20 | Considerations for Non-Transfusion-Dependent β -Thalassaemia | Maria Domenica Cappellini |
| 11:20 - 11:45 | Comprehensive Approach to α -Thalassaemia | Ali Amid |
| 11:45 - 12:00 | Panel Discussion and Q&A | |

12:00 - 13:30 **LUNCH BREAK**

- | | | |
|---------------|--|------------------|
| 13:30 - 13:50 | Debunking Thalassaemia Myths  | Hanny Al-Samkari |
|---------------|--|------------------|

13:50 - 15:00 **SESSION 5. NEW AND EMERGING ADVANCES IN CURE AND CARE**

Chairpersons: Stefano Rivella & Janet Kwiatkowski

- | | | |
|---------------|--|-------------------|
| 13:50 - 14:10 | Curative Therapies for Haemoglobin Disorders | Janet Kwiatkowski |
| 14:10 - 14:30 | Advances in Treatment | Kevin H.M Kuo |
| 14:30 - 14:50 | Patient Testimonial: How Advances in Treatment Changed My Life | Aliya Rinaldi |
| 14:50 - 15:00 | Panel Discussion and Q&A | |

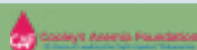
15:00 - 15:30 **COFFEE BREAK**

15:30 - 17:00 **SESSION 6. THRIVING WITH THALASSAEMIA: HEALTH & WELLNESS**

Chairpersons: Maria Hadjidemetriou, Tamara Schryver & Dina Steagall

- | | | |
|---------------|--|----------------------|
| 15:30 - 15:45 | Nutrition & Diet: Eating Right to Stay Strong | Tamara Schryver |
| 15:45 - 16:00 | Exercise & Movement: What's Safe & What's Beneficial? | Maya Bloomberg |
| 16:00 - 16:15 | Travel & Safety: Tips for Patients on the Go | Maria Hadjidemetriou |
| 16:15 - 16:30 | Family Planning: Fertility in thalassaemia | Kinga Malinowski |
| 16:30 - 16:45 | Ageing: Coping with thalassaemia over 40 | Kevin H.M Kuo |
| 16:45 - 17:00 | Panel Discussion and Q&A | |

17:30 **RECEPTION HOSTED BY**



SUNDAY, 13 JULY 2025

HALL: REGENCY EF

07:00 - 08:00 CONTINENTAL BREAKFAST - Hall: Regency CD

08:00 - 10:00 **SESSION 7. MEET THE EXPERTS – INSIGHTS INTO APPROPRIATE THALASSAEMIA CARE**
Chairperson: Maria Domenica Cappellini & Dimitrios Farmakis

08:00 - 09:30 Meet the Experts: Q&A on Living with Thalassaemia and Optimizing Care Pathways

Janet Kwiatkowski
Kinga Malinowski
Ellen Fung

09:30 - 10:00 **CONCLUDING REMARKS**

This panel will provide key takeaways from the conference, highlight major discussions, and outline the next steps for continued collaboration between patients, healthcare professionals, and global partners.

Janet Kwiatkowski
Craig Butler
Robert Ficarra
Lily Cannon
Bessie Calabria

10:00 - 10:30 COFFEE BREAK

2nd RARE ANAEMIA INTERNATIONAL NETWORK (RAIN) SUMMIT **HALL: REGENCY EF**

JOINT PROGRAMME

10:30 - 13:00 **SESSION 8. RARE ANAEMIAS: ADVANCING KNOWLEDGE AND ACCESS TO QUALITY CARE**
Chairpersons: Hanny Al-Samkari & Lily Cannon

10:30 - 10:50 Evolving Therapeutic Strategies for Rare Anaemias

Hanny Al-Samkari

10:50 - 11:30 Hearing from the community - Best Practices from:

- Carl Lander- PKDIA Foundation (UK)
- Andre Luiz Rodrigues Bastos - HEMOPE (Brazil)
- Addassa Follett - UK Sickle Cell Society (UK)
- Shenelle Maharaj - The Society for Inherited & Severe Blood Disorders T&T Limited – (T&T)

11:30 - 12:00 Access to Treatment: Knowledge and Education for Rare Anaemias

Rachael F. Grace

12:00 - 12:30 Diagnostic Challenges in Rare Anaemia

Narla Mohandas

12:30 - 13:00 **Interactive Discussion: Future actions and activities**

Panel Discussion



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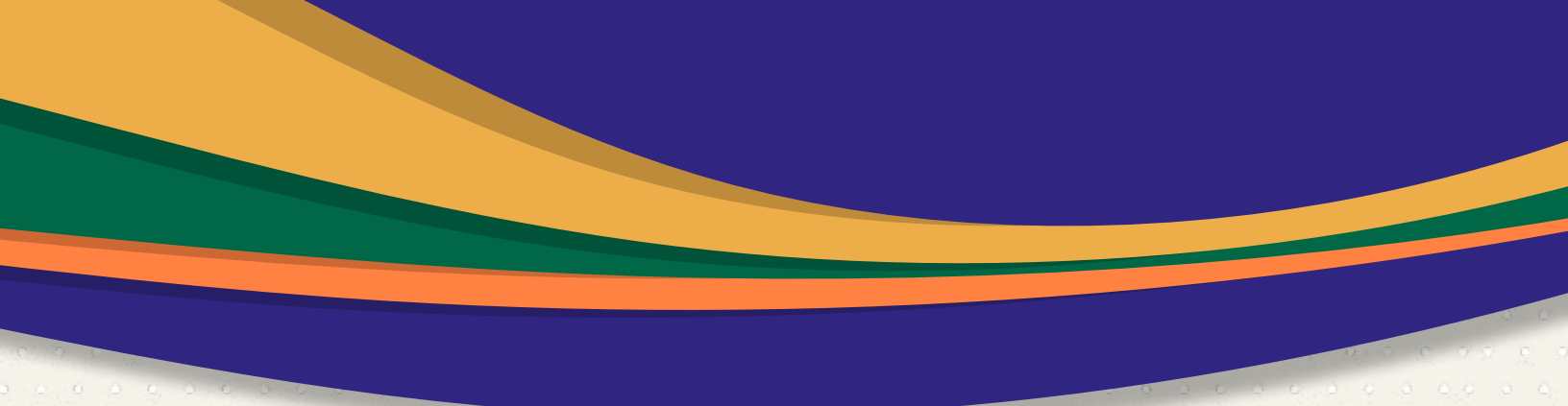
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