

1st TIF Pan American Conference on Thalassaemia and Other Haemoglobin Disorders & 2nd RAIN Summit

11 - 13 July 2025 | Hyatt Regency Crystal City
Washington D.C., USA

PROGRAMME

CME UNITS PENDING

Organised by:



In collaboration with:



Supported by:



1st TIF Pan American Conference on Thalassaemia and Other Haemoglobin Disorders & 2nd RAIN Summit

HIGHLIGHTS

- Advances in Thalassaemia and Sickle Cell Disease Management
- Gene and Cell-Based Therapies: Future Prospects
- Multidisciplinary Care Models for Hemoglobinopathies
- 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) supported by the Pan American Network for Haemoglobin Disorders (PANHD), represents a landmark event aimed at advancing care, research, and advocacy for hemoglobin disorders across the Americas. Taking place from July 11–13, 2025, at the Hyatt Regency Crystal City, Washington, D.C., this conference brings together healthcare professionals, patients, caregivers, policymakers, and stakeholders to address the unique challenges faced by individuals living with thalassaemia, sickle cell disease, and other hemoglobinopathies in the region.

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

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

- The fundamentals of clinical management of haemoglobin disorders
- Enhancing knowledge and awareness
- Fostering collaboration and networking
- Addressing unmet patient needs
- Strengthening national and regional strategies
- To amplify patient advocacy and engagement
- To celebrate achievements and inspire future action



ORGANISING COMMITTEE

Dr Panos Englezos President, Thalassaemia International Federation, Cyprus

Dr Ralph Colasanti National President, Cooley's Anemia Foundation, USA

Dr Androulla Eleftheriou Executive Director, Thalassaemia International Federation, Cyprus

Mr Craig Butler National Executive Director, Cooley's Anemia Foundation, USA

SPEAKERS & CHAIRPERSONS

Mr Robert Ficarra Board Member, Cooley's Anemia Foundation. Former TIF Board Member, USA

Dr Sandra Loggetto Paediatric Haematology at the Haematology Department of Sabara Children's Hospital Sao Paulo, Brazil, and at São Paulo Blood Bank, GSH Group, Brazil

Dr Ali Amid Director, Provincial Pediatric Hemoglobinopathy Program, BC Children's, Hospital, University of British Columbia, Vancouver, BC, Canada

Ms Aliya Rinaldi Member of Cooleys Anemia Foundation, USA

Dr Ashutosh Lal Professor of Clinical Pediatrics, UCSF School of Medicine
Comprehensive Thalassemia Center & The Iron Disorders Program
UCSF Benioff Children's Hospital, Oakland, USA

Mrs Bessie Calabria President of the Thalassemia Foundation of Canada, Board Member of the Thalassaemia International Federation, Canada

Dr David A. Jacobsohn, MD, MBA Professor of Pediatrics, Chief, Division of Blood and Marrow Transplantation Children's National Hospital, George Washington University School of Medicine and Health Sciences, Washington, DC, USA

Dr Farzana Sayani Medical Director Blood Disorders Program, Toronto General Hospital, Toronto, Associate Professor Medicine, University of Toronto, Canada

Dr Hanny Al-Samkari Classical Hematologist and Clinical Investigator, The Peggy S. Blitz, Endowed Chair in Hematology/Oncology, Co-Director, Hereditary Hemorrhagic Telangiectasia Center, Massachusetts General Hospital
Associate Professor of Medicine, Harvard Medical School, USA

Ms Isabely Di Roberto Member of Brazilian Thalassaemia Association (ABRASTA), Brazil

Dr Janet Kwiatkowski Professor of Pediatrics, Perelman School of Medicine at the University of Pennsylvania, Director of the Thalassemia Center at Children's Hospital of Philadelphia, USA

Prof. John Wood Professor of Pediatrics, Radiology, and Bioengineering at the University of Southern California and Director of Cardiovascular at Children's Hospital Los Angeles, USA



Dr Kathleen Durst	Social worker, Cooley's Anemia Foundation, New York, USA
Dr Kevin H.M Kuo	Associate Professor, Division of Hematology, Department of Medicine, Faculty of Medicine, University of Toronto, Associate Professor (status), Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, Canada
Mrs Lily Cannon	Deputy Manager, Thalassaemia International Federation, Cyprus
Mr Lucio Miguel Bongiorno	Member of Argentinian Thalassaemia Association (ATA), Argentina
Prof. Maria Domenica Cappellini	Professor of Internal Medicine at the University of Milan and Chief of the Rare Diseases Centre at the Fondazione IRCCS Policlinico Hospital, Milan, Italy
Mrs Maria Hdjidemetriou	Board Member of Cooley's Anemia, Board Member of the Thalassaemia International Federation, New York, USA
Ms Maya Bloomberg	Classical Hematology Nurse Practitioner, Sylvester Comprehensive Cancer Center, Jackson Memorial Hospital, USA
Prof. Narla Mohandas	Distinguished Scientist, Head, Laboratory of Red Cell Physiology, Head of the laboratory of red cell physiology at New York Blood Center Enterprises, Vice President, American Society of Hematology, New York, USA
Prof. Paul Telfer	Honorary Consultant Haematologist and Paediatric Haematologist Barts Health NHS Trust, Clinical Director, East London and Essex Clinical Haemoglobinopathy Network-Sickle Cell Disease, East London, Essex, SE England Haemoglobinopathy Network- Thalassaemia, United Kingdom
Dr Rachael F. Grace	Attending Physician, Pediatric Hematology, Boston Children's Hospital Associate Professor, Harvard Medical School, Boston, Massachusetts, USA
Ms Radhika Sawh	Board Member of Cooley's Anemia Foundation, USA
Mr Rob Mannino	Member of Cooleys Anemia Foundation, USA
Ms Shenelle Maharaj	Member of the Society for Inherited & Severe Blood Disorders Trinidad and Tobago Limited, Trinidad & Tobago
Prof. Stefano Rivella	Professor of Pediatrics - Children's Hospital of Philadelphia Leader of the RNA Gene Therapeutics Group - Penn Institute for RNA Innovation, Scientific Director of CuRED, Philadelphia, USA
Dr Tamara Schryver	Co-Founder and President at Thrive with Pyruvate Kinase Deficiency Organization, USA
Dr Thomas Coates	Professor of Pediatrics and Pathology, Section Head, Hematology, Cancer and Blood Disease Institute, University of Southern California Keck School of Medicine, Childrens Hospital Los Angeles, USA



DRAFT PROGRAMME

FOR HEALTHCARE PROFESSIONALS

DAY 1: FRIDAY, 11 JULY 2025

Joint Session

15:00 – 15:30 OPENING CEREMONY AND WELCOME ADDRESSES		
	<ul style="list-style-type: none"> The Thalassaemia International Federation Cooley's Anaemia Foundation 	<p>P. Englezos</p> <p>R. Colasanti</p>
15:30 – 17:00 SESSION 1. KEYNOTE SPEECHES Chairpersons: Androulla Eleftheriou & Ralph Colasanti		
15:30 – 15:55	<ul style="list-style-type: none"> The Role of Patient Organizations in Shaping Health and Social Policies 	A. Eleftheriou
15:55 – 16:20	<ul style="list-style-type: none"> Bridging Gaps and Addressing Challenges in the Care of Haemoglobin Disorders: Past – Present - Future 	PAHO
16:20 – 16:50	<ul style="list-style-type: none"> Patient Voices: Personal Journeys Across the Americas: My Truth, My Story <i>Testimonials from: USA, Canada, Brazil, Argentina, and Trinidad & Tobago</i> 	<p>R. Mannino – USA</p> <p>B. Calabria – Canada</p> <p>I. Roberto – Brazil</p> <p>L.M. Bongiorno – Argentina</p> <p>S. Maharaj - Trinidad & Tobago</p>
16:50 – 17:00	<ul style="list-style-type: none"> The Work and Contribution of TIF (Video) 	
17:00 – 19:00 ORAL ABSTRACT PRESENTATIONS		

DAY 2 – SATURDAY, 12 JULY 2025

08:00 – 10:00 SESSION 2. STANDARD OF CARE FOR HAEMOGLOBIN DISORDERS – THALASSAEMIA Chairpersons: Sandra Loggetto & John Wood		
08:00 – 08:25	<ul style="list-style-type: none"> Blood Transfusion Management: Ensuring Safety, Efficacy, and Long-Term Patient Well-Being 	T. Coates
08:25 – 08:45	<ul style="list-style-type: none"> Iron Overload and Monitoring - Strategies for effective chelation and long-term patient care 	P. Telfer
08:45 – 09:05	<ul style="list-style-type: none"> Systemic Complications in Thalassaemia: Endocrine Disorders, Liver Disease, Fertility Challenges 	M.D. Cappellini
09:05 – 09:25	<ul style="list-style-type: none"> Cardiac Health 	J. Wood
09:25 – 09:45	<ul style="list-style-type: none"> Enhancing Care for α-Thalassemia: Recognizing Challenges and Realizing Opportunities 	A. Amid
09:45 – 10:00	<ul style="list-style-type: none"> 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 & Paul Telfer		
10:30 – 10:55	<ul style="list-style-type: none"> Current and Emerging Drug Therapies for Haemoglobin Disorders 	K. Kuo
10:55 – 11:20	<ul style="list-style-type: none"> Gene-Based Therapies for Haemoglobin Disorders: Progress and Future Prospects 	S. Rivella
11:20 – 11:45	<ul style="list-style-type: none"> Haematopoietic Stem Cell Transplantation (HSCT): Current Experience with a Proven Curative Approach for Haemoglobin Disorders 	D.A. Jacobsohn
11:45 – 12:00	<ul style="list-style-type: none"> Panel Discussion and Q&A 	
12:00 – 13:30 LUNCH BREAK		



DRAFT PROGRAMME

FOR HEALTHCARE PROFESSIONALS

13:30 – 15:00 SESSION 4. PROVIDING OPTIMUM CARE TO PATIENTS WITH HAEMOGLOBIN DISORDERS: CONSIDERATIONS BEYOND THE TREATING PHYSICIAN

Chairpersons: Thomas Coates & MD Cappellini

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|---------------|---|--------------|
| 13:30 – 13:50 | • Navigating the Transition from Paediatric to Adult Care | F. Sayani |
| 13:50 – 14:10 | • Challenges in Managing Thalassaemia and other Haemoglobin Disorders in Multi-cultural Setting | A. Lal |
| 14:10 – 14:30 | • The Role of Nursing in the Care for Haemoglobin Disorders | M. Bloomberg |
| 14:30 – 14:50 | • The Contribution of the Social Worker in the Care of Haemoglobin Disorders | K. 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: Farzana Sayani & Ashutosh Lal

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| 15:30 – 15:50 | • The Role of National Registries in Improving Patient Care and Disease Management | M. D. Cappellini |
| 15:50 – 16:10 | • National Prevention Programme and Neonatal Screening – the Keys to the More Effective Control of Haemoglobin Disorders | P. Telfer |
| 16:10 – 16:30 | • The Role of Reference Centres and Regional Networking in Enhancing Patient Care | J. Kwiatkowski |
| 16:30 – 16:45 | • Panel Discussion and Q&A | |

16:45 – 18:00 SESSION 6. FUTURE DIRECTIONS IN HEMOGLOBINOPATHY CARE

Chairpersons: Hanny Al-Samkari & David A. Jacobsohn

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

18:00 – 19:00 RECEPTION

DAY 3: SUNDAY, 13 JULY 2025

08:00 – 10:00 CASE PRESENTATIONS

10:00 – 10:30 COFFEE BREAK

Joint Session

2ND RARE ANAEMIAS INTERNATIONAL NETWORK SUMMIT

10:30 – 13:00 SESSION 7. RARE ANAEMIAS: ADVANCING KNOWLEDGE AND ACCESS TO QUALITY CARE

Chairpersons: Hanny Al-Samkari & Lily Cannon

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|---------------|--|---------------|
| 10:30 – 10:50 | • Evolving Therapeutic Strategies for Rare Anaemias | H. Al-Samkari |
| 10:50 – 11:30 | • Hearing from the community - Best Practices from:
- CDA Foundation
- PKD Foundation
- SCDAA
- Aplastic Anemia Foundation | TBC |
| 11:30 – 12:00 | • Access to Treatment: Knowledge and Education for Rare Anaemias | R. F. Grace |
| 12:00 – 12:30 | • Diagnostic Challenges in Rare Anaemia | N. Mohandas |
| 12:30 – 13:00 | • Interactive Discussion: Future actions and activities | |



DRAFT PROGRAMME

FOR PATIENTS/PARENTS

DAY 1: FRIDAY, 11 JULY 2025

Joint Session

15:00 – 15:30 OPENING CEREMONY AND WELCOME ADDRESSES		
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16:20 – 16:50	<ul style="list-style-type: none"> Patient Voices: Personal Journeys Across the Americas: My Truth, My Story <i>Testimonials from: USA, Canada, Brazil, Argentina, and Trinidad & Tobago</i> 	<p>R. Mannino – USA</p> <p>B. Calabria – Canada</p> <p>I. Roberto – Brazil</p> <p>L.M. Bongiorno – Argentina</p> <p>S. Maharaj - Trinidad & Tobago</p>
16:50 – 17:00	<ul style="list-style-type: none"> The Work and Contribution of TIF (Video) 	
17:00 – 18:00 SESSION 2. BUILDING CONNECTIONS: PATIENT PANEL DISCUSSION Chairpersons: TBC		
17:00 – 18:00	<ul style="list-style-type: none"> Patient Panel: Insights from the Region 	

DAY 2 – SATURDAY, 12 JULY 2025

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	<ul style="list-style-type: none"> Coping with Anxiety & Stress: Strategies for Mental Resilience 	K. Durst
08:20 – 08:40	<ul style="list-style-type: none"> Building Confidence & Overcoming Challenges in Daily Life 	B. Calabria
08:40 – 09:00	<ul style="list-style-type: none"> How to Talk About Your Condition with Family & Friends 	M. Hadjidemetriou
09:00 – 09:20	<ul style="list-style-type: none"> Navigating the Transition from Paediatric to Adult Care 	F. Sayani
09:20 – 10:00	<ul style="list-style-type: none"> 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 & Ali Amid		
10:30 – 10:55	<ul style="list-style-type: none"> Management of Transfusion-Dependent β-Thalassaemia: Key Messages 	P. Telfer
10:55 – 11:20	<ul style="list-style-type: none"> Considerations for Non-Transfusion-Dependent β-Thalassaemia 	M.D. Cappellini
11:20 – 11:45	<ul style="list-style-type: none"> Comprehensive Approach to α-Thalassaemia 	A. Amid
11:45 – 12:00	<ul style="list-style-type: none"> Panel Discussion and Q&A 	
12:00 – 13:30 LUNCH BREAK		



DRAFT PROGRAMME

FOR PATIENTS/PARENTS

13:30 – 15:00 SESSION 5. NEW AND EMERGING ADVANCES IN CURE AND CARE

Chairpersons: Stephano Rivella & Janet Kwiatkowski

13:30 – 13:50	• Curative Therapies for Haemoglobin Disorders	J. Kwiatkowski
13:50 – 14:10	• Advances in Treatment	K. Kuo
14:10 – 14:25	• Patient Testimonial: How my Life has Changed	A. Rinaldi
14:25 – 14:45	• To be Confirmed	TBC
14:45 – 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

15:30 – 15:45	• Nutrition and Diet: Eating Right to Stay Strong	T. Schryver
15:45 – 16:00	• Exercise and Movement: What's Safe and What's Beneficial?	M. Bloomberg
16:00 – 16:15	• Travel and Safety: Tips for Patients on the Go	TIF
16:15 – 16:30	• Family Planning: Fertility in Thalassaemia	R. Sawh
16:30 – 16:45	• Ageing: Coping with Thalassaemia over 40	F. Sayani
16:45 – 17:00	• Panel Discussion and Q&A	

18:00 – 19:00 RECEPTION

DAY 3: SUNDAY, 13 JULY 2025

08:00 – 10:00 SESSION 7. CONCLUDING SESSION: ADDRESSING UNMET PATIENT NEEDS

08:00 – 08:20	• To be confirmed	
08:20 – 08:40	• The Value of Collaboration, Partnerships, Reference Centres and Networking	A. Eleftheriou
08:40 – 09:00	• To be confirmed	
09:00 – 09:20	• The Active & Meaningful Patient Engagement at the Decision-Making Level	L. Cannon
09:20 – 10:00	• Panel Discussion and Q&A	

10:00 – 10:30 COFFEE BREAK

2ND RARE ANAEMIAS INTERNATIONAL NETWORK SUMMIT

10:30 – 13:00 SESSION 8. RARE ANAEMIAS: ADVANCING KNOWLEDGE AND ACCESS TO QUALITY CARE

10:30 – 10:50	• Evolving Therapeutic Strategies for Rare Anaemias	H. Al-Samkari
10:50 – 11:30	• Hearing from the community - Best Practices from: - CDA Foundation - PKD Foundation - SCD AA - Aplastic Anemia Foundation	TBC
11:30 – 12:00	• Access to Treatment: Knowledge and Education for Rare Anaemias	R. F. Grace
12:00 – 12:30	• Diagnostic Challenges in Rare Anaemia	N. Mohandas
12:30 – 13:00	• Interactive Discussion: Future actions and activities	



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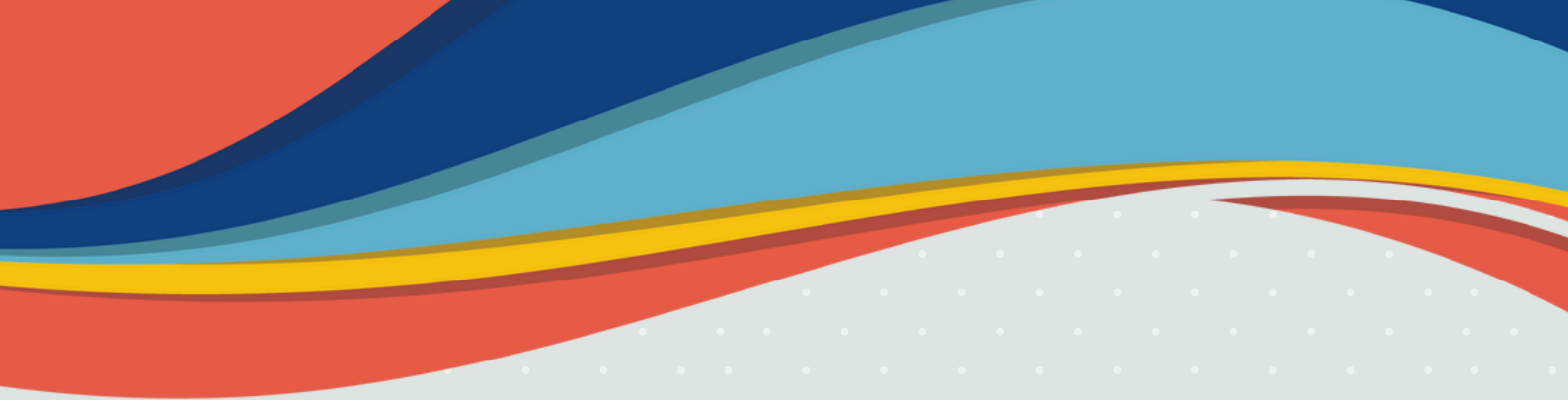
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