



PATIENTS/PARENTS PROGRAMME

'Empowering Patients'

DAY 1 - SATURDAY, 26TH SEPTEMBER 2015

10.30 – 12.30	Symposium 1: Blood Safety, Treatment - Iron load monitoring & Infections	Chairs: Suthat Fucharoen/ Michael Angastiniotis 10:30 – 10:55 - Blood safety - Erica wood 10:55 – 11:20 - Blood Transfusion in Thalassaemia - Michael Angastiniotis 11:20 – 11:45 - Iron Load Monitoring & Chelation – Chi Kong Li 11:45 – 12:10 - Infections in Thalassaemia – Suthat Fucharoen 12:10 – 12:30 - Panel Discussion
12.30 – 14.00	Lunch	
14.00 - 15.00	Symposium 2: Treatment updates	Chairs: Anuja Premawardhena/Nguyen Thi Thu Há 14:00 – 14:25 - An overview of NTDT – Anuja Premawardhena 14:25 – 14:50 - Iron Chelation in NTDT – Ibrahim Mohamed Hishamshah 14:50 – 15:00 - Panel Discussion
15.00 - 15.30	Coffee	

<p>15.30 - 17.15</p>	<p>Symposium 3: Common Complications: Endocrine, Cardiac and Liver</p>	<p>Chairs: Athanassios Aessopos/ Shau Yin Ha</p> <p>15:30 – 15:50 - Growth and skeletal changes - Shau Yin Ha</p> <p>15:50 – 16:10 - Sexual development and problems of adolescence – Michael Angastiniotis</p> <p>16:10 – 16:30 - Cardiac Complications – Athanassios Aessopos</p> <p>16:30 – 16:50 - Liver Complications – Vip Viprakasit</p> <p>16:50 – 17:55 - Panel Discussion</p>
<p>18.00 - 20.00</p>	<p>Opening ceremony</p>	<p>Chairs: Panos Englezos/ Nguyen Anh Tri</p> <p>TIF President – Panos Englezos</p> <p>NIHBT/ViTA President – Nguyen Anh Tri</p> <p>Minister of Health of Vietnam - tbc</p> <p>ASEAN – tbc</p> <p>Keynote 1. The global picture - Androulla Eleftheriou</p> <p>Keynote 2. Gene Therapy – Philippe Leboulch</p> <p>Traditional Music Show</p>

DAY 2 - SUNDAY, 27TH SEPTEMBER 2015 – EMPOWERING PATIENTS

09.00 - 10.00	Symposium 4: HSCT & Quality and efficacy of Drugs	Chair: Bach Quoc Khanh/ Suradej Hongeng 09:00 – 09:25 - Haematopoietic Stem Cell Transplantation (HSCT) – Who can benefit – Suradej Hongeng 09:25 – 09:50 - Quality and efficacy of life-saving drugs in thalassaemia – Mahmood Hadipour Dehshal 09:50 – 10:00 - Panel Discussion
10.00 - 10.30	Coffee	
10.30 - 12.30	Symposium 4: Quality of Life, Measuring Iron Overload	Chair: Duong Ba Truc/Mahmood Hadipour Dehshal 10:30 – 11:00 - Psychosocial support – Michael Angastiniotis 11:00 – 11:30 - Novel Erythropoiesis Stimulating Agents In Thalassaemia – John Porter 11:30 – 12:00 - MRI Technologies for Measurement of Tissue Iron Concentrations – Tim St Pierre 12:00 – 12:30 - Panel discussion
12.30 - 14.00	Lunch	
14.00 - 15.00	Symposium 5: Capacity Building: Associations	Chairs: Shobha Tuli/ Androulla Eleftheriou 14:00 – 14:25 - The role of associations in education and advocacy – Androulla Eleftheriou 14:25 – 14:40 - Organising an association: Building up infrastructure – Shobha Tuli 14:40 – 15:00 - The Maldives Patients' Survey – Jeehan Saleem
15.00 - 15.30	Coffee	
15.30 - 17.30	Symposium 6: Capacity Building: Clinical Trials on Gene therapy: A to Z	Chairs: Mahmood Hadipour Dehshal/Michele Rhee 15:30 – 15:55 - A patient's journey – Viresh Piplani 15:55 – 16:20 - Clinical Trials: Understanding clinical trials – Mahmood Hadipour Dehshal 16:20 – 16:45 - The patients' perspective on clinical trials – Androulla Eleftheriou 16:45 – 17:10 - Gene therapy: Michele Rhee 17:10 – 17:30 - Panel Discussion
17.30 - 17.45	Closing remarks	Panos Englezos, Prof Nguyen Anh Tri