



## Agenda

### The 2<sup>nd</sup> Southeast Asia Rare Disease Summit

8:30 – 9:00	<b>Registration</b>
9:00 – 9:25	<b>Welcome remarks</b> <b>Peter Streibl</b> , General Manager, Takeda Thailand, <b>Prof. Thanyachai Sura M.D.</b> , President, Medical Genetics and Genomics Association <b>Prof. Duangrurdee Wattanasirichaigoon M.D.</b> , President, Thai Rare Disease Foundation, Thailand <b>Prof. Prakitpunthu Tomtitchong, MD</b> , President, Medical Association of Thailand,
9:25 – 9:35	<b>Keynote Speech: Sustainable Access - a fundamental element of the right to better health</b> by The Prime Minister Srettha Thavisin or Representative of the Prime Minister
9:35 – 9:45	<b>Opening ceremony</b> <b>Assoc. Prof. Cherdchai Tontisirin, MD.</b> , Vice Minister of Public Health, Thailand
9:45 – 10:10	<b>Defining a New Future for National Access Policy to Address Unmet Needs in Rare Diseases</b> <b>Dr. Khoo Yoong Khean</b> , Scientific Officer, SingHealth Duke-NUS Global health Institute (SDGHI) and Centre of Regulatory Excellence (CORE), Duke-NUS Medical School Singapore
10:10 – 10:35	<b>Optimal Approach Exchange on Innovative Funding</b> <b>Dr. Jasmine Pwu, PhD</b> , Chief Executive Officer, Data Science Center, College of Medicine, Fu-Jen Catholic University
10:35 – 11:55	<b>Coffee Break</b>

10:55 – 11:15

### **Evolving and Future of Rare Disease Policy in Thailand**

**Assoc. Prof. Cherdchai Nopmaneejumrulers, MD**, Chairman of the Working Group of Care System Development for Rare Diseases, NHSO

Deputy Dean of Service Innovations and Corporate Value, Faculty of Medicine, Siriraj Hospital, Mahidol University

**Prof. Kanya Suphapeetiporn, MD, PhD**, Co-Chair of the Working Group of Care System Development for Rare Diseases, NHSO

Head of Medical Genetics and Metabolism Unit, Department of Pediatrics, Faculty of Medicine, Chulalongkorn University

11:15 – 12:15

### **Fostering Commitment and Contribution: Enabling Sustainable Diagnosis and Access to Innovative Treatments**

#### **Panel Discussion**

Moderator:

**Michellew Erwee**, Global Head of Access to Medicines, Takeda

Panelists:

**Assoc. Prof. Cherdchai Nopmaneejumrulers, MD**, Chairman of the Working Group of Care System Development for Rare Diseases, NHSO

Deputy Dean of Service Innovations and Corporate Value, Faculty of Medicine, Siriraj Hospital, Mahidol University

**Dr. Tae Sok Kun**, Head of Paediatric Unit, University of Malaya

**Dr. Durhane Wong-Rieger**, President, Asia Pacific Alliance of Rare Disease Organisations (APARDO)

**Dr. Camencita D. Padilla**, MAHPS, Chancellor, University of the Philippines, Manilla

**Prof. Dr. Joyce Lam**, Senior Consultant Hematologist, KK Women's and Children's Hospital

12:15 – 13:30

**Lunch**

- 13:30 –14:00**      **Patient Organization, a Crucial Voice for an Inclusive Patient-Centered Policy**  
Ekawat Suwantaroj, Vice President of Thai Hemophilia Patient Club  
Board of Directors, The World Federation of Hemophilia
- 14:00 – 15:00**      **Patient Empowerment as a Critical Driver to Maximize Capacity in Patient-Centric Access Policy**  
**Panel Discussion: Key Country Representatives:**  
Moderator: **Rajakath R**, Principal Partner, Manefeste LLP  
Program Director, Rare Disorder Society Singapore  
Visiting Expert, Duke Nus Medical School  
Executive Director, Rainbow Across Borders Limited  
Panelists: Thailand, Malaysia, Singapore, Indonesia, and Philippines representatives
- 15:00 – 15:15**      **Coffee Break**
- 15:15 – 15:45**      **Southeast Asia 5 Year Patient Organization Roadmap**  
Thailand, Malaysia, Singapore, Indonesia, and Philippines representatives
- 15:45 – 16:00**      **Commitment Statement to Empower Patients’Voices**  
Dion Warren, Regional Head, Southeast Asia & India, Takeda