



Asia Pacific
Alliance of Rare
Disease Organisations



Philippine Society
for Orphan Disorders

APARDO

November 22-24 2024

CONFERENCE

Philippines



Venue: Dusit Thani Manila



Agenda

DAY 0 : Friday, November 22 (2:00PM – 8:00PM PHT)

Time PHT	Program
2:00 – 3:00PM	APARDO Board Meeting
3:00 – 4:00PM	APARDO Alliance of Companies Meeting
4:00 – 5:30PM	APARDO Member Update Meeting
6 :00– 8:00PM	Welcome Reception

2024 Conference Theme: Changing the Paradigm

DAY 1: Saturday, November 23 (8:00AM – 6:00PM PHT)

Time PHT	Program	Speaker(s)
8:00 – 8:30AM	Registration	
8:30 – 8:45AM	Conference Welcome & Opening	Ms. Cynthia Magdaraog (President, Philippine Society for Orphan Disorders) Dr. Carmencita Padilla (National Scientist, National Academy of Science and Technology; Emeritus Professor, College of Medicine, University of the Philippines Manila / APARDO)
8:45 – 9:00AM	Getting to know the Filipino Rare Disease Patient Community - Video and Showcasing the patient group achievements and activities	



Asia Pacific
Alliance of Rare
Disease Organisations



Philippine Society
for Orphan Disorders

APARDO CONFERENCE

Philippines

November 22-24 2024



Time PHT	Program	Speaker(s)
9:00 – 9:15AM	Conference Welcome Remarks Theme: Changing the Paradigm	Dr. Durhane Wong-Rieger (President, APARDO / Canadian ORD)
	Introduction of the Secretary, Department of Health, Philippines	Dr. Carmencita Padilla
9:15 – 9:40AM	Keynote Address: Advancing Rare Disease as a Key Priority in Universal Health Coverage in Philippines	Dr. Teodoro Herbosa (Secretary, Department of Health)
	Session 1 – Newborn Bloodspot Screening	MC/Moderator: Dr. Rachel Yang (Chinese Alliance of Rare Diseases (CHARD) / APARDO)
9:40 – 10:00AM	<u>Keynote Presentation</u> WHO NBS initiatives and focus	Dr. Ayesha de Costa (Scientist, Dept of Maternal, newborn, child and adolescent health, World Health Organisation)
10:00 – 10:20AM	<u>Keynote Presentation</u> The Global Screening Eco-System in 2024	Dr. Bradford L. Therrell (Director, U.S. National Newborn Screening and Global Resource Center)
10:20 – 10:50AM	Panel Response –Newborn Bloodspot Screening –APAC Country response to Keynotes and local applications	Dr. Melanie Alcausin (Director, Institute of Human Genetics, Philippines) Dr. Meow-Keong Thong (Professor and Consultant Clinical Geneticist, Genetics & Metabolism Unit, Department of Paediatrics, Faculty of Medicine, University of Malaya, Malaysia) Dr. Phuoc Huy Do (Vietnamese Organization for Rare Diseases) Dr Ting Teck Wah (Senior Consultant Genetics Service, Department of Paediatrics, KK Women's and Children's Hospital (KKH) Singapore)
10:50 – 11:10AM	Morning Tea Break	
	Session 2 – Genomic Sequencing: Newborns and Beyond	MC/Moderator: Ms. Monica Ferrie
11:10 – 11:30AM	GenSCAN – An Australian Research Initiative	Virtual: Dr. Tiffany Boughtwood (Managing Director, Australian Genomics)



Asia Pacific
Alliance of Rare
Disease Organisations



Philippine Society
for Orphan Disorders

APARDO

November 22–24 2024

CONFERENCE

Philippines



Time PHT	Program	Speaker(s)
11:30 – 12:10PM	NBS, Exome Sequencing, Genome Sequencing	Prof Herawati Sudoyo (Principal Investigator, Genome Diversity and Diseases Laboratory Mochtar Riady Institute of Nanotechnology, Indonesia) Dr. Eva Cutiongco-de la Paz (Executive Director, National Institutes of Health, Philippines) Dr. Duangrurdee Wattanasirichaigoon (Professor of Pediatrics and Medical Genetics at the Department of Pediatrics, Faculty of Medicine Ramathibodi Hospital, Mahidol University, Thailand)
12:10 – 12:40PM	Panel Response and Discussion - Key elements for success - Overcoming barriers – with ‘who’ and ‘how’ - Development steps from screening to sequencing	Patient, Regional and Professional Representatives: Ms. Yukiko Nishimura (Asrid, Japan) Ms. Eka Fetratika (Indonesia Rare Disorders (IRD)) Dr. Claudia CY Chung (Senior Researcher, Hong Kong Genome Institute, The University of Hong Kong)
12:40 – 1:40PM	Lunch and Networking	
	Session 3 – Diagnostic and Care Models	MC/Moderator: Dr. Durhane Wong-Rieger
2:00 – 2:30PM	<u>Presentation: AI-enabled technology</u> - As a diagnostic tool in primary care - Auto-reassessment	Prof. Dr. Christian J. Hendriksz (A Rare Cause)
2:30 – 3:10PM	<u>Video Presentation: Diagnostic Models</u> - Centre's of Excellence – Brazil / Romania / Saudi Arabia	Dr. Durhane Wong-Rieger
3:10 – 3:30PM	<u>Panel Response and Discussion</u> - Q: How do we get there at local level? - Q: What could be possible at regional level? - Overcoming barriers	Dr. Dong Dong (Illness Challenge Foundation / APARDO) Dr. Rachel Yang Dr. Carmencita Padilla
3:30 – 4:00PM	Afternoon Break	
	Session 4 – The role of Healthcare Professional and Patient Communities in Prevention and Screening	MC/Moderator: Dr. Rachel Yang



Asia Pacific
Alliance of Rare
Disease Organisations



Philippine Society
for Orphan Disorders

APARDO CONFERENCE

Philippines

November 22–24 2024



Time PHT	Program	Speaker(s)
4:00 – 5:00PM	<p><u>Panel Discussion</u></p> <p>Response to the day</p> <ul style="list-style-type: none"> - Reflections on screening and sequencing - Reflections on AI enabled technology in diagnostics - What care models need to support the diagnostic journey - The diversity challenge - Keeping pace with technology for patient groups 	<p>Ms. Nadiah Hanim (Malaysian Rare Disorders Society)</p> <p>Ms. Eka Fetranika (Indonesia)</p> <p>Dr. Duangrurdee Wattanasirichaigoon (Thailand)</p> <p>Mr. Ekawat Suuwantaroj (Director, World Federation of Hemophilia, Thailand)</p> <p>Dr. Melanie Alcausin (Philippines)</p> <p>Ms. Jasmine Goh (Genetics, Assistant Nurse, KK Women's and Children's Hospital (KKH), Singapore)</p>
5:00 – 6:00PM	<p>Networking – drinks and canapes</p> <p>International Showcase</p> <ul style="list-style-type: none"> - Participants can pre-register for a 10 minute slot to showcase Asia Pacific patient led innovation 	

Access to Drugs, Treatment and Therapies for LMIC's

DAY 2 : Sunday, November 24 (9:00AM – 3:45PM PHT)

Time PHT	Program	
9:00 – 9:15AM	<p>Welcome to Day 2</p> <p>Highlights and Key Learnings from Day 1</p> <p>Understanding the Access and struggles of LMICs</p>	Dr. Carmencita Padilla
	<p>Session 1 – The Access Challenge</p> <p>Designing and delivering for LMIC's</p>	<p>MC/Moderator:</p> <p>Dr. Durhane Wong-Rieger</p>
9:15 – 9:30AM	<p><u>Presentation: Global Determinants for access</u></p> <ul style="list-style-type: none"> - Economic - Cultural - Financial - Political - Health System - Awareness 	Dr. Durhane Wong-Rieger
	<p>Session 2 – Access to Treatment Innovation</p>	<p>MC/Moderator:</p> <p>Dr. Carmencita Padilla</p>



Asia Pacific
Alliance of Rare
Disease Organisations



Philippine Society
for Orphan Disorders

APARDO CONFERENCE

Philippines

November 22–24 2024



Time PHT	Program	
9:30 – 10:30AM	<p><u>Panel Discussion: Strategies that Work</u></p> <ul style="list-style-type: none"> - Cross-border compassionate program/fund - Clinical trial – NBS –Advanced therapies –Gene therapy - HTA: Modified Multi-criteria Evidence Assessment & Analysis - Scaled Negotiated Pricing 	<p>Ms. Emmylou Casanova (Philippines Patient Advocate - GPP)</p> <p>Ms. Nadiyah Hanim (Malaysia)</p> <p>Dr. Duangrurdee Wattanasirichaigoon (Thailand)</p> <p>Dr. Phuoc Huy Do (Vietnam)</p> <p>Atty. Jose Ochave (SVP, United Laboratories, Inc)</p> <p>Ms. Doreen Tan (Sanofi)</p>
10:30 – 11:00AM	Morning Tea Break	
	Session 3 – Workshop Designing Access Strategies for LMIC's	MC/Moderator: Dr. Durhane Wong-Rieger
11:00 – 12:30PM	<p><u>Small Group Case Studies Problem-Solving</u></p> <p>Format:</p> <ul style="list-style-type: none"> • Preassigned mixed groups (10 persons) • Access Challenge: Individual/Family with Rare Condition and Treatment Option(s) • Context: Country, Access Pathway, Healthcare Infrastructure • Financial Situation <p>Questions:</p> <ul style="list-style-type: none"> - What works and what doesn't work - What does (good) access look like - What support is needed to support equitable access 	
12:30 – 1:00PM	Working Lunch Break	
1:00 – 1:20PM	<p><u>Parallel activities:</u></p> <ol style="list-style-type: none"> 1. Group Leaders to prepare report out 2. Panel by Industry Reps 	<p>Moderator: Dr. Carmencita Padilla</p> <p><u>Industry:</u></p> <p>Ms. Anne-Sophie Chalandon (Sanofi)</p> <p>Mr. Lee Davelaar (Pfizer)</p> <p>Ms. Flaminia Macchia (AstraZeneca/Alexion)</p> <p>Mr. Logan Caragata (Roche)</p> <p>Dr. Shirlene Badger (Illumina)</p>
1:20 – 2:15PM	Report out from each Breakout Group (3 mins each)	<p><u>Policy Makers:</u></p> <p>Dr Jose Gerard Belimac (Division Chief, Child, Adolescent & Maternal Health, Department of Health, Philippines)</p> <p>Dato' Dr Mohd Azman bin Yacob (Director of the Medical Development Division, Ministry of Health, Malaysia)</p> <p>Mrs. Hansa Thaisri (Deputy Director, Medical Life Sciences Institute, Department of Medical Sciences, Ministry of Public Health, Thailand)</p>
2:15 – 2:45PM	Reaction from Policy Makers	
2:45 – 3:00PM	Summary of Breakout groups (by Moderator)	



Asia Pacific
Alliance of Rare
Disease Organisations



Philippine Society
for Orphan Disorders

APARDO

November 22-24 2024

CONFERENCE

Philippines



Time PHT	Program	
3:05 – 3:15PM	Group Photo	
	Session 4 – Next Steps and Close	
3:15 – 3:30PM	<u>WHO Resolution</u> Pilot Project: ENDING the Rare Disease Diagnostic Odyssey: Together – ONE Step At A Time	Ms. Monica Ferrie Dr. Durhane Wong-Rieger Dr. Rachel Yang Ms. Flaminia Macchia
3:30 – 3:45PM	Joint closing statements APARDO and PSOD	Dr. Durhane Wong-Rieger Dr. Carmencita Padilla