



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	<b>Ms. Cynthia Magdaraog</b> (President, Philippine Society for Orphan Disorders)  <b>Dr. Carmencita Padilla</b> (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	

Sponsored by:

Gold



Silver



Bronze





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	<b>Dr. Durhane Wong-Rieger</b> (President, APARDO / Canadian ORD)
	Introduction of the Secretary, Department of Health, Philippines	<b>Dr. Carmencita Padilla</b>
9:15 – 9:40AM	Keynote Address: Advancing Rare Disease as a Key Priority in Universal Health Coverage in Philippines	<b>Dr. Teodoro Herbosa</b> (Secretary, Department of Health)
	Session 1 – Newborn Bloodspot Screening	MC/Moderator: <b>Dr. Rachel Yang</b> (Chinese Alliance of Rare Diseases (CHARD) / APARDO)
9:40 – 10:00AM	<u>Keynote Presentation</u> WHO NBS initiatives and focus	<b>Dr. Ayesha de Costa</b> (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	<b>Dr. Bradford L. Therrell</b> (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	<b>Dr. Melanie Alcausin</b> (Director, Institute of Human Genetics, Philippines) <b>Dr. Meow-Keong Thong</b> (Professor and Consultant Clinical Geneticist, Genetics & Metabolism Unit, Department of Paediatrics, Faculty of Medicine, University of Malaya, Malaysia) <b>Dr. Phuoc Huy Do</b> (Vietnamese Organization for Rare Diseases) <b>Dr Ting Teck Wah</b> (Senior Consultant Genetics Service, Department of Paediatrics, KK Women's and Children's Hospital (KKH) Singapore)
10:50 – 11:10AM	Morning Tea Break	

Sponsored by:

Gold



Silver



Bronze





Asia Pacific  
Alliance of Rare  
Disease Organisations



Philippine Society  
for Orphan Disorders

# APARDO CONFERENCE

Philippines

November 22–24 2024



Time PHT	Program	Speaker(s)
	Session 2 – Genomic Sequencing: Newborns and Beyond	MC/Moderator: <b>Ms. Monica Ferrie</b>
11:10 – 11:30AM	GenSCAN – An Australian Research Initiative	Virtual: <b>Dr. Tiffany Boughtwood</b> (Managing Director, Australian Genomics)
11:30 – 12:10PM	NBS, Exome Sequencing, Genome Sequencing	<b>Prof Herawati Sudoyo</b> (Principal Investigator, Genome Diversity and Diseases Laboratory Mochtar Riady Institute of Nanotechnology, Indonesia) <b>Dr. Eva Cutiongco-de la Paz</b> (Executive Director, National Institutes of Health, Philippines) <b>Dr. Duangrurdee Wattanasirichaigoon</b> (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:  <b>Ms. Yukiko Nishimura</b> (Asrid, Japan) <b>Ms. Eka Fetranika</b> (Indonesia Rare Disorders (IRD)) <b>Dr. Claudia CY Chung</b> (Senior Research Fellow, The University of Hong Kong, Hong Kong)
12:40 – 1:40PM	Lunch and Networking	
	Session 3 – Diagnostic and Care Models	MC/Moderator: <b>Dr. Durhane Wong-Rieger</b>
2:00 – 2:30PM	<u>Presentation: AI-enabled technology</u> - As a diagnostic tool in primary care	<b>Prof. Dr. Christian J. Hendriksz</b> (A Rare Cause)
2:30 – 3:10PM	<u>Video Presentation: Diagnostic Models</u> - Centre’s of Excellence – South America / Europe / Asia	<b>Dr. Durhane Wong-Rieger</b>
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	<b>Dr. Dong Dong</b> (Illness Challenge Foundation / APARDO) <b>Dr. Rachel Yang</b> <b>Dr. Carmencita Padilla</b>
3:30 – 4:00PM	Afternoon Break	

Sponsored by:

Gold



Silver



Bronze







Asia Pacific  
Alliance of Rare  
Disease Organisations



Philippine Society  
for Orphan Disorders

# APARDO

November 22-24 2024

# CONFERENCE

Philippines



Time PHT	Program	Speaker(s)
	Session 4 – The role of Healthcare Professional and Patient Communities in Prevention and Screening	MC/Moderator: <b>Dr. Rachel Yang</b>
4:00 – 5:00PM	<u>Panel Discussion</u>  Response to the day - 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	<b>Ms. Nadiyah Hanim</b> (Malaysian Rare Disorders Society) <b>Ms. Eka Fetranika</b> (Indonesia) <b>Dr. Duangrurdee Wattanasirichaigoon</b> (Thailand) <b>Mr. Ekawat Suwantaroj</b> (Director, World Federation of Hemophilia, Thailand) <b>Dr. Melanie Alcausin</b> (Philippines) <b>Ms. Jasmine Goh</b> (Genetics, Assistant Nurse, KK Women's and Children's Hospital (KKH), Singapore)
5:00 – 6:00PM	Networking – drinks and canapes  International Showcase - Participants to showcase Asia Pacific patient led innovation in 10-minute slots	

## 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	Welcome to Day 2 Highlights and Key Learnings from Day 1 Understanding the Access and struggles of LMICs	<b>Dr. Carmencita Padilla</b>
	Session 1 – The Access Challenge - Designing and delivering for LMIC's	MC/Moderator: <b>Dr. Durhane Wong-Rieger</b>
9:15 – 9:30AM	<u>Presentation: Global Determinants for access</u> - Economic - Cultural - Financial - Political - Health System - Awareness	<b>Dr. Durhane Wong-Rieger</b>
	Session 2 – Access to Treatment Innovation	MC/Moderator: <b>Dr. Carmencita Padilla</b>
9:30 – 10:30AM	<u>Panel Discussion: Strategies that Work</u> - Cross-border compassionate program/fund - Clinical trial – NBS –Advanced therapies –Gene therapy - HTA: Modified Multi-criteria Evidence Assessment & Analysis - Scaled Negotiated Pricing	<b>Ms. Emmylou Casanova</b> (Philippines Patient Advocate - GPP) <b>Ms. Nadiyah Hanim</b> (Malaysia) <b>Dr. Duangrurdee Wattanasirichaigoon</b> (Thailand) <b>Dr. Phuoc Huy Do</b> (Vietnam) <b>Atty. Jose Ochave</b> (SVP, United Laboratories, Inc)

Sponsored by:

Gold



Silver



Bronze





Asia Pacific  
Alliance of Rare  
Disease Organisations



Philippine Society  
for Orphan Disorders

# APARDO CONFERENCE

Philippines

November 22-24 2024



Time PHT	Program	
10:30 – 11:00AM	Morning Tea Break	
	Session 3 – Workshop Designing Access Strategies for LMIC's	MC/Moderator: <b>Dr. Durhane Wong-Rieger</b>
11:00 – 12:30PM	<p><u>Small Group Case Studies Problem-Solving</u></p> <p>Format:</p> <ul style="list-style-type: none"> <li>• Preassigned mixed groups (10 persons)</li> <li>• Access Challenge: Individual/Family with Rare Condition and Treatment Option(s)</li> <li>• Context: Country, Access Pathway, Healthcare Infrastructure</li> <li>• Financial Situation</li> </ul> <p>Questions:</p> <ul style="list-style-type: none"> <li>- What works and what doesn't work</li> <li>- What does (good) access look like</li> <li>- What support is needed to support equitable access</li> </ul>	
12:30 – 1:00PM	Working Lunch Break	
1:00 – 1:20PM	<p><u>Parallel activities:</u></p> <ol style="list-style-type: none"> <li>1. Group Leaders to prepare report out</li> <li>2. Panel by Industry Reps</li> </ol>	<p>Moderator: <b>Dr. Carmencita Padilla</b></p> <p><u>Industry:</u></p> <p><b>Ms. Anne-Sophie Chalandon</b> (Sanofi)  <b>Ms. Shamie Zainal</b> (Pfizer)  <b>Ms. Lotis Ramin</b> (AstraZeneca/Alexion)  <b>Dr. Shirlene Badger</b> (Illumina)</p> <p><u>Policy Makers:</u></p> <p><b>Dr Jose Gerard Belimac</b>  (Division Chief, Child, Adolescent &amp; Maternal Health, Department of Health, Philippines)</p> <p><b>Dato' Dr Mohd Azman bin Yacob</b>  (Director of the Medical Development Division, Ministry of Health, Malaysia)</p> <p><b>Mrs. Hansa Thaisri</b>  (Deputy Director, Medical Life Sciences Institute, Department of Medical Sciences, Ministry of Public Health, Thailand)</p> <p><b>Dr. Irene Lorinda Indalao</b>  (Leader, Biomedical Genome Science Initiative, The National Center for Biomedical and Genomic Science Institute, The Ministry of Health of Indonesia)</p>
1:20 – 2:15PM	Report out from each Breakout Group (3 mins each)	
2:15 – 3:00PM	Reaction from Policy Makers	
3:00 – 3:15PM	Summary of Breakout groups (by Moderator)	
3:15 – 3:30PM	Group Photo	
	Session 4 – Next Steps and Close	
3:30 – 3:45PM	Joint closing statements APARDO and PSOD	<b>Dr. Durhane Wong-Rieger</b> <b>Dr. Carmencita Padilla</b>

Sponsored by:

Gold



Silver



Bronze

