



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
8:00 – 8:30AM	Registration
8:30 – 8:45AM	Conference Welcome & Opening
8:45 – 9:15AM	Getting to know the Filipino Rare Disease Patient Community - Video and Showcasing the patient group achievements and activities
9:15 – 9:25AM	Conference Welcome Remarks Theme: Changing the Paradigm
9:25 – 9:30AM	Introduction of the Secretary
9:30 – 9:50AM	Keynote Address: Advancing Rare Disease as a Key Priority in Universal Health Coverage in Philippines



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Time PHT	Program
	Session 1 – Newborn Bloodspot Screening
9:50 – 10:10AM (20 mins)	<u>Keynote Presentation</u> WHO NBS initiatives and focus
10:10 – 10:30AM (20 mins)	<u>Keynote Presentation</u> The Global Screening Eco-System in 2024
10:30 – 10:50AM (20 mins)	Panel Response –Newborn Bloodspot Screening –APAC Country response to Keynotes and local applications
10:50 – 11:10AM	Morning Tea Break
	Session 2 – Genomic Sequencing: Newborns and Beyond
11:10 – 11:30AM	GenSCAN – An Australian Research Initiative
11:30 – 11:50AM	Taiwan: NBS, Exome Sequencing, Genome Sequencing
11:50AM – 12:10PM	Targeted and Population Genome Sequencing – Qatar
12:10 – 12:40PM	Panel Response and Discussion - Key elements for success - Overcoming barriers – with ‘who’ and ‘how’ - Development steps from screening to sequencing
12:40 – 1:40PM	Lunch and Networking
	Session 3 – Diagnostic Models and Technologies
2:00 – 2:30PM	<u>Presentation: AI-enabled technology</u> - As a diagnostic tool in primary care - Auto-reassessment
2:30 – 3:10PM	<u>Presentation: Intensive Diagnostic Models</u> - Centre’s of Excellence –The Brazil model (20 mins) - Multi-site Centres of Excellence - China (20 mins)



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Time PHT	Program
3:10 – 3:30PM	<p><u>Panel Response and Discussion</u></p> <ul style="list-style-type: none"> <li>- Q: How do we get there at local level?</li> <li>- Q: What could be possible at regional level?</li> <li>- Overcoming barriers</li> </ul>
3:30 – 4:00PM	Afternoon Break
	Session 4 – The role of Healthcare Professional and Patient Communities in Prevention and Screening
4:00 – 5:00PM	<p><u>Panel Discussion</u></p> <p>Response to the day</p> <ul style="list-style-type: none"> <li>- Reflections on screening and sequencing</li> <li>- Reflections on AI enabled technology in diagnostics</li> <li>- What care models need to support the diagnostic journey</li> <li>- The diversity challenge</li> <li>- Keeping pace with technology for patient groups</li> </ul>
5:00 – 6:00PM	<p>Networking – drinks and canapes</p> <p>International Showcase</p> <ul style="list-style-type: none"> <li>- Participants can pre-register for a 10 minute slot to showcase Asia Pacific patient led innovation</li> </ul>



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## Access to Drugs, Treatment and Therapies for LMIC's

### DAY 2 : Sunday, November 24 (9:00AM - 3:30PM 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 APARDO's commitment to changing the paradigm and driving change
	Session 1 - Access to Treatment Innovation
9:15 - 9:35AM	<u>Presentation: Global Determinants for Access</u> - Economic - Cultural - Financial - Political - Health System - Awareness
9:35 - 10:10AM	<u>Presentations on Strategies that Work (7 mins each)</u>
10:10 - 10:30AM	<u>Panel Discussion - Session 1 Presenters</u> - Q: What is the relationship to the Global determinants? - Q: Are there similarities, that are transferrable? - Q: What is the role of each of the stakeholders? - Q: What are the policy levers?
10:30 - 11:00AM	Morning Tea Break
	Session 2 - The Access Challenge Designing and delivering for LMIC's
11:00 - 11:50AM	<u>Presentations on Access (10 mins each)</u> - Generic label options and opportunities - Local production and manufacturing - Partnering with Foundations - Institutional and academic partnerships - Repurposing drugs



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Time PHT	Program
11:50AM – 12:15PM	<p><u>The Access Challenge Panel</u></p> <ul style="list-style-type: none"> <li>- How do we get it done locally and regionally</li> <li>- What does equitable access look like</li> <li>- Aspiration v Reality; low-cost access options</li> <li>- What support needs to be in place to support equitable access</li> </ul>
12:15 – 1:00PM	Lunch Break
	Session 3 – Meeting demand with equity Designing and delivering for LMIC's
1:00 – 2:15PM	<p><u>Workshop - Briefing on the 2 Case Studies / Assign Breakout Groups &amp; Questions</u></p> <p>Small Group Case Studies Problem-Solving - Designing access solutions and changes required – framework access determinants and condition case studies</p> <p>Format:</p> <ul style="list-style-type: none"> <li>• Preassigned mixed groups (6 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>
2:15 – 3:00PM	<p><u>Parallel activities:</u></p> <ol style="list-style-type: none"> <li>1. Group Leaders to prepare report out</li> <li>2. Short Presentation</li> </ol> <p>Report out from each Breakout Group (3 mins each)</p> <p>Summary of Breakout groups (by Moderator)</p>
3:00 – 3:15PM	Group Photo
	Session 4 – Next Steps and Close
3:15 – 3:30PM	<p>Joint closing statements</p> <p>APARDO and PSOD</p>