



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	Speaker(s)
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	Philippine Society for Orphan Disorders (PSOD)
8:45 – 9:30AM	Getting to know the Filipino Rare Disease Patient Community	Patient Advocate Groups (PAGs)
9:30 – 9:40AM	Conference Welcome Remarks Theme: Changing the Paradigm	Dr. Durhane Wong-Rieger (APARDO)
9:40 – 9:50AM	Keynote Address: Advancing Rare Disease as a Key Priority in Universal Health Coverage in Philippines	Department of Health (Philippines) representative



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Time PHT	Program	Speaker(s)
9:50 – 10:00AM	Response to Minister on behalf of RD Community	Ms. Cynthia Magdaraog (PSOD)
	Session 1 – Newborn Bloodspot Screening	
10:00 – 10:20AM	<u>Keynote Presentation</u> The Global Screening Eco-System in 2024	
10:20 – 10:40AM	<u>Keynote Presentation</u> WHO NBS initiatives and focus	WHO Geneva representative
10:40 – 11:00AM	Panel Response –Newborn Bloodspot Screening –APAC Country response to Keynotes and local applications	
11:00 – 11:30AM	Morning Tea Break	
	Session 2 – Genomic Sequencing: Newborns and Beyond	
11:30 – 11:50AM	GenSCAN – An Australian Research Initiative	
11:50AM – 12:10PM	China Genome Sequencing Initiatives	
12:10 – 12:30PM	Exploring the Middle East Programs – Saudi/UAE	UAE representative
12:30 – 1:00PM	Panel Response and Discussion - Key elements for success - Overcoming barriers – with ‘who’ and ‘how’ - Development steps from screening to sequencing	
1:00 – 2:00PM	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	



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Time PHT	Program	Speaker(s)
2:30 – 3:10PM	<p><u>Presentation: Intensive Diagnostic Models</u></p> <ul style="list-style-type: none"> - Centre's of Excellence –The Brazil model - An APAC example – China 	
3:10 – 3:30PM	<p><u>Panel Response and Discussion</u></p> <ul style="list-style-type: none"> - How do we get there at local level? - What could be possible at regional level? - Overcoming barriers 	
3:30 – 4:00PM	Afternoon Break	
	Session 4 – The role of Healthcare Professional and Patient Communities and 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"> - 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 	
5:00 – 6:00PM	<p>Networking</p> <p>International Showcase</p>	



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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	Speakers
9:00 - 9:15AM	Welcome to Day 2 Highlights and Key Learnings from Day 1	Dr. Carmencita Padilla
9:15 - 9:30AM	A patient perspective on access to treatment (Philippines)	
9:30 - 9:45AM	APARDO's commitment to change the paradigm and drive change	Dr. Durhane Wong-Rieger (APARDO)
	Session 1 - The Global and Asia Pacific Treatment Access Eco-System	
9:45 - 10:15AM	<u>Keynote Presentation (30 mins)</u> Global Determinants for Access - Economic - Cultural - Financial - Political - Health System - Awareness	
10:15 - 10:35AM	<u>Asia-Pacific Response (20 mins)</u> - How are we placed on the global determinant scale? - The APAC horizon	
10:35 - 11:00AM	Morning Tea Break	
	Session 2 - The Supply Challenge Designing and delivering for LMIC's	
11:00 - 11:20AM	Presentation: Innovative models for making treatment available and accessible	
11:20AM - 12:10PM	<u>Presentation series (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	Speakers
12:10 – 12:45PM	<u>Supply Challenge Panel</u> How do we get it done locally and regionally	
12:45 – 1:00PM	Lunch Break	
	Session 3 – Meeting demand with equity Designing and delivering for LMIC's	
1:00 – 1:40PM	<u>Presentation series</u> - Improving finance and funding through innovative models - Clinical Trials - Designing for LMIC's - Bio-consortiums – coming to the table with intent	
1:40 – 2:00PM	<u>Panel Discussion</u> - What works and what doesn't work - What does access look like - What needs to be in place to support equitable access	
	Session 4 – Creating and Demonstrating Impact	
2:00 – 2:20PM	Presentation: Demonstrating return on investment	
2:20 – 2:40PM	<u>Presentation series</u> - Preventative and Proactive Health Investment - Measuring economic burden	
2:40 – 3:00PM	<u>Panel Discussion</u> - Influencing decision makers by changing the paradigm - Building the appetite for change	
3:00 – 3:15PM	Group Photo	
	Session 5 – Next Steps and Close	
3:15 – 3:30PM	Closing Statements	Dr. Durhane Wong-Rieger (APARDO) Dr. Carmencita Padilla