

**APARDO Annual Meet 2019**  
Regional Collaborations for Global Change  
*In Collaboration with Taiwan Foundation for Rare Disorders & Rare Diseases International*  
18-19 October 2019, Taiwan  
Chang Yung-Fa Foundation International Convention Center

**OBJECTIVES:**

- Assure APARDO operates as an effective and sustainable regional network of patients' organizations to represent patient interests in global entities and initiatives and to serve as a valuable resource to member organizations.
- Create and support a shared vision of patient-centred rare disease policy for Asia Pacific region that is economically, politically, and socially viable and can also be adapted to individual countries.
- Gain knowledge about components of rare disease policy and plans, share best practices (re: programs for diagnosis, registries, centers of excellence, comprehensive care, community support, access to therapies, and research), and understand how these relate to broader policies affecting (for example) health, human rights, disabilities, economic development and research.
- Gain knowledge about progress of APEC Rare Disease Action Plan for translation in the region as well as leverage to advance rare disease actions in own national and local settings
- Gain new knowledge and share best practices for raising awareness and advocating on behalf of rare diseases in general and for specific issues at global, regional, national, and local levels
- Develop vision, operational framework, and commitment for APARDO as a regional alliance of rare disease patient organizations with capacity to support regional initiatives (like APEC), national policies, and local issues
- Develop skills and strategies for advancing rare diseases with public, policy and decision makers, rare disease patient groups, healthcare providers, industry, and other stakeholders.

TIME	ACTIVITY	SPEAKERS
<b>18 Oct</b>		
	Arrival of Delegates Offsite APARDO Dinner Venue: Brasserie at Regent Taipei Hotel	
<b>19 Oct : Regional Collaborations for Global Rare Disease (full day)</b> Venue: Room 803 Chang Yung-Fa Foundation International Convention Center		
08:30 – 09:00	Registration and coffee	-
09:00 – 09:15	Welcome Introduction and Objectives	Ritu Jain (APARDO Chair) Dr. Shuan-Pei Lin (TFRD Chair)

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09:15 – 10:30	<p><b>Panel 1:</b> Building APARDO Regional Alliance Panel Discussion How does collaboration advance rare disease in Asia-Pacific region?</p> <ul style="list-style-type: none"> <li>• What are the benefits of working as a region? Whose interests are advanced?</li> <li>• What are the challenges of working as a region? Whose interests are potentially harmed?</li> <li>• Where do you see opportunities to collaborate over the next five years?</li> </ul> <p>Planning for Action</p>	<p>Facilitator: Durhane Wong-Rieger</p> <p>Panelists: Ritu Jain (APARDO) Rachel Yang (CORD, China) KP Tsang (HK Rare Disease Alliance) Yukiko Nishimura (Asrid, Japan) Lisa Foster, (NZORD, New Zealand), Sanaullah Syed (IORD, India) ALL</p>
10:30 – 10:45	Coffee Break	
10:45– 12:00	<p><b>Panel 2:</b> Amplifying the Patient Voice: Individual to National to Regional Alliances Discussion</p> <ul style="list-style-type: none"> <li>• What are individual experiences and how have these experiences motivated formation of alliances?</li> <li>• What have been benefits of a common voice (disease specific or national)?</li> <li>• What have been challenges of building and sustaining collective voice?</li> <li>• What are ways in which RD groups can work collectively in a country (with and without a formal alliance)?</li> </ul> <p>Planning for Action</p>	<p>Facilitator: Ritu Jain</p> <p>Panelists: Serena Wu (Taiwan Rare Disease Foundation) Alba Ancochea (FEDER/ALIBER, Spain) Edmund Lim (We Care Journey, Malaysia) Nidhi Swarup (Crohn's &amp; Colitis Society of Singapore)</p> <p>All</p>
12:00 – 13:00	Lunch	
13:00—14:30	<p><b>Panel 3:</b> Global Initiatives for Rare Disease – Opportunities and Challenges Global RD Organizations</p> <ul style="list-style-type: none"> <li>• Rare Disease International</li> <li>• IRDiRC and Patient Advocacy Constituent Committee</li> </ul>	<p>Facilitator: Rachel Yang</p> <p>Presenters: Ritu Jain Yukiko Nishimura</p>



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	<p><i>Global Agencies and Policy Frameworks</i></p> <ul style="list-style-type: none"> <li>Asia Pacific Economic Coordination (APEC) Rare Disease Framework</li> <li>UN Universal Health Coverage &amp; WHO</li> </ul> <p><i>Global Programs and Initiatives</i></p> <ul style="list-style-type: none"> <li>Global Commission to End Diagnostic Odyssey for Children with Rare Diseases</li> <li>IRDiRC Rare Disease “Medicines for All” Working Group</li> </ul> <p>Discussion</p>	<p>Matthew Bellgard</p> <p>Durhane Wong-Rieger</p> <p>All</p>
14:30 – 14:45	Tea Break	
14:30 – 15:45	<p><b>Panel 4:</b> Multi-stakeholder Collaboration and Engagement</p> <p><b>Opening Statements:</b> From your specific stakeholder perspective, what have been the most important contributions made to advancing rare disease at local, national, regional or global levels?</p> <ul style="list-style-type: none"> <li>European Regional Policy</li> <li>Clinician/Researcher</li> <li>Healthcare Educator</li> <li>Pharmaceutical Industry</li> <li>Patient Engagement</li> <li>Health Technology Assessment</li> <li>Regulatory</li> </ul> <p>Discussion</p> <ul style="list-style-type: none"> <li>How has the landscape for rare disease changed over the past years? What are advances and set-backs?</li> <li>How have you have collaborated on policy, program, or practice to affect rare disease?</li> <li>What are the most important trends in environment, economics, technology, health, or society that will influence rare disease policy and practice over the next five years?</li> </ul> <p>Commentary</p>	<p>Facilitator: Safiyya Gassman</p> <p>Panelists</p> <p>Dr. Carmencita Padilla (University of the Philippines. Manila)</p> <p>Dr. SY Chu (Buddhist Tzu Chi General Hospital, Hualien, TW)</p> <p>Safiyya Gassman (Pfizer, New York)</p> <p>Karla Ruiz de Castilla (Latin American Patients Academy, Peru)</p> <p>Ya Hsin Wang (Psoriasis Association Taiwan)</p> <p>Dr. Nikki Kitikiti (Duke-NUS Medical School, Singapore)</p> <p>All</p>

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15:45-15:50	<b>Rare Hero Award</b> Presented to: Serena Wu	All
15:50 – 16:15	<b>Summary</b> Key learning and what next	All
16:15	END OF APARDO PROGRAM DAY 1	
16:30 – 17:30	APARDO AGM <ul style="list-style-type: none"> <li>• Financial Report</li> <li>• Membership</li> <li>• Activity Report</li> <li>• Election of Board</li> <li>• Proposed Changes to Constitution</li> <li>• AOB</li> </ul> APARDO Dinner Venue: Caesar Park Hotel Taipei No. 38, Section 1, Zhongxiao West Road Zhongzheng District 100 Taipei	

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<b>20 Oct</b>		
Venue: Chang Yung-Fa Foundation International Convention Center		
Optional	TFRD and THGS Symposium (full day)	
Optional	Gala Dinner Venue: Sheraton Grand Taipei	
<b>21 Oct am (8:30 – 12:00)</b>		
Venue: Chang Yung-Fa Foundation International Convention Center		
Morning  8:30 – 9:00	APARDO: Using APEC Rare Disease Framework to Develop Local and National Action <a href="#">Room 1002 Chang Yung-Fa Foundation International Convention Center</a> Welcome and Set-Up Brief Overview of APEC Rare Disease Framework	Durhane Wong-Rieger Eric Obscherning, APEC Life Sciences Innovation Forum Duangrurdee Wattanasirichaigoon, Thai Board of Pediatrics Lucky S. Slamet, Indonesia
9:15 – 10:15 or 10:30 – 11:30	Issue#1: Public awareness and sustainable support for rare disease 1. What is the current status awareness and support (level of public awareness, types of government support, other stakeholder initiatives)? 2. <b><i>In What Ways Might</i></b> ... (patient groups convince public health to address challenges of rare disease) 3. Identify facilitators and barriers 4. Create Action Plan to build on facilitator and address barrier	Facilitators: Durhane, Rachel, Karla, Safiyya  Lead: TBD Round 1: Group A Round 2: Group B
9:15 – 10:15 or 10:30 – 11:30	Issue #2: Genetic/genomic testing for rare disease diagnosis and care 1. What is the current status of testing (what tests are performed for whom under what circumstances) 2. <b><i>In What Ways Might</i></b> ... (patient groups advocate for timely, accessible genetic testing) 3. BIG IDEA: What bold idea could jump start testing? 4. What are possible solutions? What is best solution? 5. Create Action Plan to build on facilitators and address barriers	Facilitators: Durhane, Rachel, Karla, Safiyya  Lead: Carmencita Padilla  Round 1: Group B Round 2: Group C

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9:15 – 10:15 or 10:30 – 11:30	<p>Issue #3: Program for Accelerated Access for Rare Disease Therapies</p> <ol style="list-style-type: none"> <li>1. What is the current status of accelerated access (to therapy) and who has benefitted?</li> <li>2. <b><i>In What Ways Might</i></b> ... (patient groups work with all stakeholders to set up AA programs)</li> <li>3. Win-Win: Identify “What’s in It for Me (WIIFM)” for each stakeholder</li> <li>4. Generate possible solutions. Identify top 3.</li> <li>5. What are +’s and -’s of top solutions for each stakeholder</li> <li>6. Create Action Plan to build on facilitators and address barriers</li> </ol>	<p>Facilitators: Durhane, Rachel, Karla, Safiyya</p> <p>Lead: KP Tsang</p> <p>Round 1: Group C Round 2: Group A</p>
11:30—12:00	Sharing and Wrap up	All
Afternoon 13:30 – 17:50 Venue	<p>MOHW Taiwan Global Health Forum <i>(optional)</i></p> <p><a href="#">Taipei International Convention Center</a></p>	
<b>22 Oct : Speakers Depart</b>		