



Asia Pacific Alliance  
of Rare Disease Organisations



# APARDO SUMMIT 2019

## Post-Event Report

### ORGANIZERS:



中華民國人類遺傳學會  
TAIWAN HUMAN GENETICS SOCIETY

### SPONSORS:



The Asia Pacific Alliance of Rare Disease Organizations (APARDO) held its very successful 2019 annual Summit, *Regional Collaboration for Global Change*, in Taipei on Oct 19-21. The event, supported by Rare Diseases International, was held in conjunction with the Taiwan Foundation for Rare Disorders (TFRD), and made possible through sponsorships offered by Takeda and Pfizer.

## THE LARGEST APARDO SUMMIT TO DATE



**51 ATTENDEES**



**17 COUNTRIES**

**19** OUT OF  
**24**  
PARTICIPATED

**MEMBER  
ORGANISATIONS**

It was an open regional rare disease forum, with participants actively engaging in discussions on various topics ranging from amplifying patient voices to multi-stakeholder collaboration and engagement; to using APEC Rare Disease Framework to develop local and national action plans. It was a successful summit where the set objectives were met with the joint efforts of every attendee.

## THEMES AT THE SUMMIT

### DAY 1

The Summit started on Oct 19 morning at the Chang Yung-fa Foundation International Convention Center, with a warm welcome and an introduction by Dr Ritu Jain, the Chair of APARDO, to 51 delegates from around the world. The attendees, in a true multi-stakeholder fashion, represented rare disease patients and patient organizations, physicians and researchers, academic institutions, pharmaceutical industry representatives, and government health agencies.

The opening panel with panelists representing Singapore, China, HK, Japan, New Zealand and India, focused on the **relevance of regional alliance**. Questions debated were: why do we need a collective voice of Asia Pacific? How does collaboration advance rare diseases in Asia-Pacific? What are the challenges and benefits of working as a region? Where do we see the opportunities to collaborate over the next 5 years? The panelists shared perspectives and ideas on how national and regional organisations can work together for a stronger and louder unified voice. In addition, participants felt that a joint market might be attractive to the drug industry to justify their investment in terms of research and development and clinical trials.

The patient organization panel on **amplifying the patient voice** included representatives of patient organizations from Taiwan, Spain, Malaysia, and Singapore who shared their experiences in starting grass-root patient groups and building from ground-up. Ms. Serena Wu, one of the two founders of TFRD, showcased TFRD two decades of brilliant work which led to an orphan drug legislation in 2000, and total payment for the 56 orphan drug covering 33 rare diseases (amounting to 195 Million NTD) in 2018. Taiwan is by far one of the best economies in terms of rare disease policy and coverage, and total patient care.

The third panel on **Global Initiatives** highlighted global rare disease updates and initiatives. Representatives from Rare Disease International (RDI), the International Rare Diseases Research Consortium (IRDiRC), Asia Pacific Economic Coordination (APEC) shared exciting policy milestones such as the incorporation of rare diseases in the UN's universal health coverage declaration and RDI's memorandum of understanding with the WHO; participants also debated the significance of the of the APEC endorsed Rare Disease Action Plan and possibilities of its translation at national levels.

The last panel discussion centered on **multi-stakeholder collaboration and engagement** and included clinicians, researchers, healthcare educators, industry representatives, patient advocates, and regulators. Discussions revolved on the changing landscape of rare diseases, multi-stakeholder collaboration for the benefit of all, and trends (social, environmental, economic, technological, health trends) that have the potential to impact rare disease policy and practice in the near future.

Across all panels and discussions, participants and presenters overwhelmingly reiterated that not only is a strong regional voice a necessity but that without collaboration, singular organisations and members are significantly weakened in making the rare disease changes they seek. Participants also pledged to work together to translate global and regional policies in their countries and hoped that APARDO would offer support and guidance through the process.

The meeting ended with a presentation of the RDI Rare Hero award to Ms Serena Wu, the co-founder of TFRD. The award was presented by the Chair of RDI, Dr Durhane Wong-Rieger.



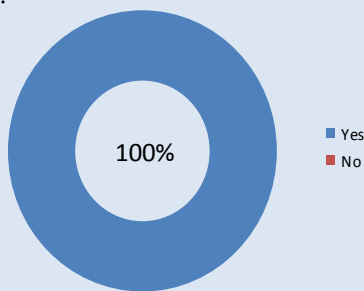
## DAY 2

The Summit continued on the 21<sup>st</sup> of October with a half-day workshop: Using APEC Rare Disease Framework to Develop Local and National Action. Facilitated by Eric Obscherning (APEC Life Sciences Innovation Forum), Safyya Gassman (Pfizer) and Durhane Wong-Rieger, the workshop offered an overview of the APEC Rare Disease Framework and explored issues such as: Public awareness and sustainable support for rare diseases, genetic/genomic testing for rare disease diagnosis, and current programs for Accelerated Access for Rare Disease Therapies. Participants identified current barriers and possibilities, considered possible avenues of collaboration and debated potential multi-stakeholder actions.

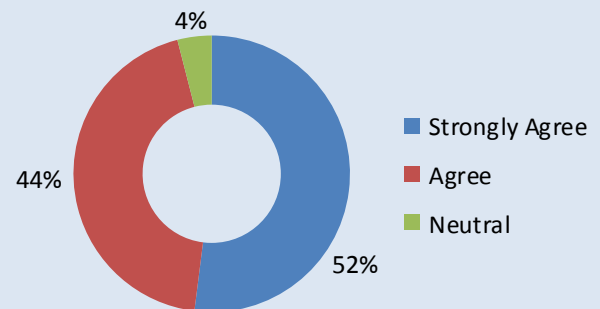
## POST-EVENT SURVEY : FINDINGS AND RECOMMENDATIONS

### FEEDBACK FROM ATTENDEES

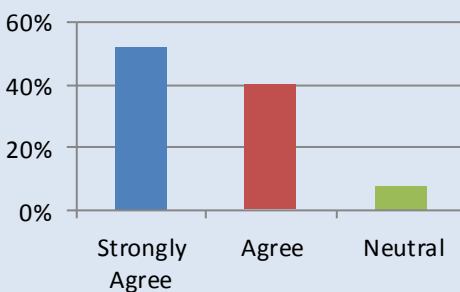
Would you be keen to participate in our future events?



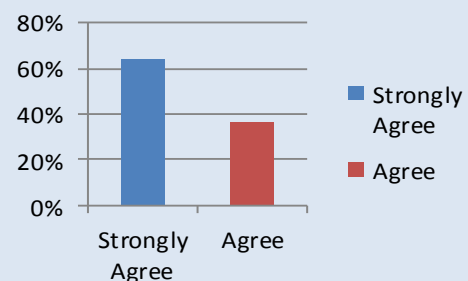
Were the Summit objectives met?



Delivered in a format that allows for effective sharing of information?



Useful to the work I'm doing?



76% Strongly Agree they will highly recommend similar APARDO events in the future, while 24% respondents Agree only

The feedback received has been overwhelmingly positive and we are extremely encouraged to know that participants benefited in various ways such as a deeper insight into the rare disease landscape, strategies and possibilities for future action and initiatives, and even, networking. The feedback has been summarized below.



## Most Valued by Participants

- Broad range of discussions creating opportunities/ideas to work on.
- Global multi-stakeholder representation with collaborative and collegial representatives.
- Information on regulatory organisation and APEC involvement.
- Patient engagement and thought leadership presentations.
- Meeting other leaders in rare disorder space.

## Key Recommendations from the Post-Event Survey

- Allocate more time over two days for sharing, brainstorming, discussions, debates
- Inclusion of regional rare disease youth activities and rare disease youth advocates initiatives.
- Requesting objective driven participation of members to create models/ evolve way forward for all.

## Suggested Priorities for APARDO

- Broad range of discussions creating opportunities/ideas to work on.
- Global multi-stakeholder representation with collaborative and collegial representatives.
- Information on regulatory organisation and APEC involvement.
- Patient engagement and thought leadership presentations.
- Meeting other leaders in rare disorder space.

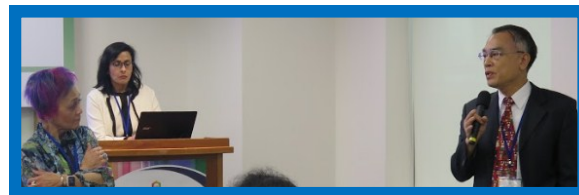
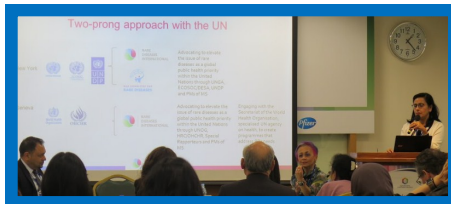
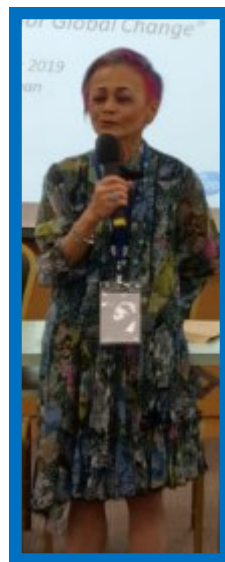
## CONCLUSION

A huge thank you to all participants, hosts, sponsors, and partners who contributed to the tremendous success of this event! We are heartened by your support and re-energised to continue and build on the momentum of this meeting to push forward our Rare Disease agenda on the regional and global stage.

We look forward to welcoming you back next year!

[admin@apardo.org](mailto:admin@apardo.org)

# HIGHLIGHTS



## WHAT PARTICIPANTS SAID

*“ APARDO 2019 offered collaboration, connection and co-operation. The richness from the threads of shared learnings, shared challenges and potential solutions combined to weave a common fabric which binds us all together despite our diversities. ”*

**Lisa Foster**  
Chief Executive  
Rare Disorders NZ (formerly NZORD)

*“ Heard a variety of complimentary perspectives, met new colleagues with similar interests, and discussed topics across the whole audience. Thank ”*

**Kristen Nowak**  
Director  
Department of Health, Western Australia

*“ Regulatory organization's involvement and APEC involvement in APARDO is awesome! Just about all stakeholders were represented, keep up the good work! ”*

**Nidhi Swarup**  
President  
Crohn's & Colitis Society of Singapore

*“ Everyone, I loved the reflection questions and the fully interactive format. ”*

**Alba Ancochea**  
Director  
Federacion Española de Enfermedades Raras (FEDER)

*“ An excellent gathering and valuable sharing of experiences and knowledge for improving health outcomes for rare disease patients and families. Taiwan Foundation for Rare Disorders (TFRD) is very honored to collaborate with APARDO to achieve the goal of the summit on “Regional Collaboration for Global Change”. As a global family, we will walk together for transforming rare lives with LOVE. ”*

**Serena Wu**  
Co-Founder/Board Member  
Taiwan Foundation of Rare Disorders

*“ I would like to commend Ritu and the APARDO team for a wonderful Annual meeting that was hosted in the beautiful city of Taipei, in collaboration with the Taiwan Foundation for Rare Disorders and Rare Disease International. The discussions were inclusive and engaging for all participants and covered a range of important topics to support those and their families living with a rare disease. The meeting highlighted the importance of APARDO representing the Rare Disease patient voice in the Asia Pacific region . I hope the APEC Rare Disease Network and APEC Action Plan on Rare Diseases can serve as helpful resources for APARDO and patients who are advocating for policy change throughout the region. ”*

**Prof. Matt Bellgard**  
Director eResearch, Queensland University of Technology, Australia  
and Chair of the APEC LSIF Rare Disease Network