

# **APARDO Strategic Objectives and 3 Year Action Plan**



**Asia Pacific  
Alliance of Rare  
Disease Organisations**

**April 2020**



# APARDO Strategic Objectives and 3 Year Action Plan

## BACKGROUND

Rare diseases affect approximately 3.5-5.9% of the worldwide population<sup>1</sup>. An estimated 200 million people in the Asia and Pacific region are living with one of the 7,000 known rare diseases, of which 80% are genetic in origin. People living with a rare disease face lengthy delays in receiving a diagnosis and often go through a diagnostic odyssey – 40% being misdiagnosed at least once. No country in Asia Pacific will be able to claim that it has achieved or successfully implemented Universal Health Coverage, if it has not adequately and equitably met the needs of people living with rare diseases<sup>2</sup>.

Founded in 2015, the Asia Pacific Alliance of Rare Disease organisations (APARDO) seeks to provide a patient advocacy-led alliance of rare disease stakeholders from the Asia-Pacific region representing national rare-disease organisations. The Alliance will work effectively to empower national rare disease organisations to advocate for better outcomes and quality of life for patients and their care-givers. The Alliance will act as a platform for delivery of support to regional and national groups by promoting best-practices and exchange of information.

In the next three years, we focus on identifying and assessing solutions for gaps between patients and policies. In addition, we aim to influence policies, building multi-stakeholder collaborations to support patient organisations, develop country-specific action plans and strengthen patient organisation networks.

## APARDO'S STRATEGIC OBJECTIVES

- 1 To identify the gaps between patients' unmet needs and existing healthcare policy on rare diseases in specific countries /jurisdictions in the region, with the aim of influencing the policies in these countries
- 2 To promote tri-partite (Government, Non-Government Organisations and business sector/industry) collaborations for addressing rare disease issues and initiate the development of country-specific national rare disease action plans across the region
- 3 To mobilize, empower and build up a network of rare disease patient leaders in the region.

## GEOGRAPHIC SCOPE

APARDO member organisations in the Asia Pacific.

## FOCUS AREAS

In alignment with the recommendations proposed in the <sup>3</sup>Rare Disease Action Plan by the Asia Pacific Economic Cooperation (APEC), as well as member expectations, APARDO's 3 Year Action Plan will be focusing on the following key areas.

- 1 Diagnosis
- 2 Orphan Drug policy
- 3 Treatment
- 4 Coordinated patient-centric care
- 5 Finance and social support.

<sup>1</sup>Nguengang Wakap, S., Lambert, D. M., Olry, A., Rodwell, C., Gueydan, C., Lanneau, V., Murphy, D., Le Cam, Y., & Rath, A. (2019). Estimating cumulative point prevalence of rare diseases: Analysis of the Orphanet database. *European Journal of Human Genetics*, 28(2), 165-173. <https://doi.org/10.1038/s41431-019-0508-0>

<sup>2</sup>Clark, H. (October, 2016). International Conference on Rare Diseases & Orphan Drugs, Cape Town. SA.

<sup>3</sup>APEC Action Plan on Rare Diseases (English). (n.d.). Asia-Pacific Economic Cooperation. Retrieved May 10, 2020, from [https://www.apec.org/-/media/Satellite/Rare-Diseases/APEC\\_ActionPlan.pdf](https://www.apec.org/-/media/Satellite/Rare-Diseases/APEC_ActionPlan.pdf)



## 3-YEAR ACTION PLAN

To strive towards the strategic objectives set out, APARDO initiates its 3 Year Action Plan within the following context:

- Development level of rare disease patient organisations in the region is highly diverse. There is no one-size-fits-all plan or framework for APARDO member organisations. This diversity is considered within our planning and strategy.
- As an umbrella organisation of NGOs in the region, APARDO commits to supporting positive changes in national rare disease policies by empowering and informing national organisations. In its endeavour to promoting improved health outcomes and quality of life, it aims to strengthen its member organisations with opportunities for connection and learning. Further, as a regional platform for rare disease patient organisations, APARDO aims to partner the more developed member organisations to mentor and support developing member organisations.

## 2020

2020 has been a difficult year with the global COVID-19 pandemic further aggravating the marginalization of the rare disease population in health services. However, APARDO remains committed to its endeavour to amplify voices of the rare disease community and strive to deliver its objectives for improved outcomes and access to care. For this, it aims to follow the plan below:

### YEAR 1 PLANNED ACTIVITIES (\*2020 / 2021)

#### CORE ACTIVITIES

- Annual Conference
- eForum for members, industry partners and other stakeholders
- Regional survey on impact of C-19 on organizational efficiency
  - Communications
  - Information sharing
  - Groundwork for Round Table of Industry
  - Enhance and make better use of the social media platform
- Engagement (1-2 countries) for gaps analysis.

#### OPTIONAL ACTIVITIES

- Programme of activity/webinar with an international partner
  - Develop standard instruments and specific tools for gaps analysis and national plan
  - Organise activities for Rare Disease Day 2021 with regional institutions and selected APARDO member organisations
- Establishment of Mentorship Working Group; Mentorship program to guide specific organisations to better select and implement tools
- Develop a position paper to overview the existing issues on rare disease in the region and make recommendations to address
- Engagement (1-2 countries) for gaps analysis.

*\*Should activities in 2020 be impossible to accomplish due to the global crisis, they will be pushed to the following year*



## YEAR 2 PLANNED ACTIVITIES (Jan 2022 to Dec 2022)

### CORE ACTIVITIES

- Annual Conference
- Annual eForum for members, industry partners and other stakeholders
- Training programme
- Organise activities for Rare Disease Day 2022 with regional institutions and selected APARDO member organisations

### OPTIONAL ACTIVITIES

- Mentorship Working Group implementation
- Engagement (1-2 countries) for national plan development and/or gaps analysis
- Network expansion
- APARDO School curriculum development; skills training for advocacy, communications, awareness and outreach through use of technology, online platforms and other resources

## YEAR 3 PLANNED ACTIVITIES (Jan 2023 to Dec 2023)

### CORE ACTIVITIES

- Annual Conference
- Annual eForum for members, industry partners and other stakeholders
- Training programme
- Organise activities for Rare Disease Day 2023 with regional institutions and selected APARDO member organisations

### OPTIONAL ACTIVITIES

- Consolidate and strengthen the Secretariat to meet APARDO's development
- Conduct 3 year strategic planning for further developments in years ahead
- Engagement (1-2 countries) for national plan development and/or gaps analysis
- Launch APARDO School; APARDO School aims to build advocacy capabilities of organisations through sharing of resources, educational materials, survey instruments etc.



## APARDO ANNUAL SPONSORSHIP PACKAGES 2021-2023

The APARDO Action Plan can not be implemented without generous financial provision to APARDO by industry partners. We cordially invite partners to sponsor the implementation of our 3 Year Action Plan.

	<b>BRONZE TIER</b>	<b>SILVER TIER</b>	<b>GOLD TIER</b>	<b>PLATINUM TIER</b>
	<b>USD 5,000</b> Quota: Unlimited	<b>USD 10,000</b> Quota: Unlimited	<b>USD 25,000</b> Quota: 4 (first-come-first-served)	<b>USD 50,000</b> Quota: 1 (first-come-first-served)
<b>SPONSOR'S ENTITLEMENTS</b>				
Corporate logo on Annual Conference backdrop	✓	✓	✓	✓
Corporate logo on slides, reports, and relevant materials of eForum	✓	✓	✓	✓
Corporate logo on APARDO website, promotional posters, and newsletters		✓	✓	✓
No. of invitations to attend Annual Conference		1 invite	2 invites	2 invites
*Exhibition space at Annual Conference			✓	✓
Nominate / invite a speaker / presenter for Annual Conference				✓
Invitation to host Lunch Symposium at Annual Conference				✓
Corporate logo on all other meeting backdrops				✓
No. of invites to attend all APARDO meetings				2 invites

\*Sponsor is responsible for booth set-up

The logo for APARDO is centered within a white hexagonal shape. The background of the entire page is composed of several overlapping geometric shapes in various colors: orange, yellow, green, teal, blue, and pink. The word "APARDO" is written in a bold, dark grey, sans-serif font.

# APARDO

If you have any questions or would like more information about rare disease in Asia Pacific, our advocates around the region will be happy to help.

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