

## Rare Diseases: A Catalyst for Global Health Transformation

### World Health Assembly 79 Side-Event

*Event under the patronage of the Arab Republic of Egypt and the Kingdom of Spain*

*Co-hosted by Rare Diseases International, the Hong Kong Rare Disease Collaborative Network (HKRDCN), the International Federation of Pharmaceutical Manufacturers and Associations (IFPMA), and Forset Hayah Foundation for Rare Diseases*

**Wednesday, 20 May, 2026**

**18:00 – 21:00 (CEST)**

**Geneva Graduate Institute**

### **Background**

**Achieving UHC requires reaching those who are hardest to reach. Rare diseases - affecting over 300 million people globally** - represent one of the most complex challenges within health systems. Small patient populations, limited clinical expertise, fragmented data, and high-cost therapies strain conventional models of care, financing, and innovation.

In May 2025, Member States took a historic step by adopting the [World Health Assembly Resolution](#) “**Rare Diseases: a global health priority for equity and inclusion,**” co-sponsored by 41 Member States. The Resolution mandates the development of a **10-Year Global Action Plan on Rare Diseases**, creating an unprecedented opportunity to:

- Strengthen health systems through integrated, cross-sector solutions guided by a 10-year roadmap with a tangible framework and clear targets
- Embed rare diseases within UHC, primary health care, and health innovation agendas
- Demonstrate how people-centred design improves outcomes across the life course

This WHA side-event marks the transition from **political commitment to implementation**, while explicitly linking rare disease action to wider global health transformation.

To bring real change in global health, many gears must turn together. People with diverse lived experience, innovative thinkers, and decision makers need to be at the same table, each sharing their perspectives, to develop a suitable solution. This is particularly true for universal health coverage (UHC), where the challenges are complex and multi-factorial, and solutions must come from “outside the box”. Rare diseases are an excellent example

of such a challenge in UHC: conventional drug development, access, and funding models are often ineffective because of the small patient populations.

The WHA Resolution is an important opportunity to ensure that rare diseases are integrated into broader UHC efforts and other health areas. Rare diseases are transversal, so this event represents an opportunity to create linkages with other health areas and stakeholders to ensure that this important health challenge is not addressed in isolation. Given the particular complexities of rare diseases, finding solutions in this space lays the foundation for expanding these solutions to other health areas.

## **Agenda**

Time	Item	Notes
18:00-18:05	Opening & Housekeeping by the Event Facilitator: <b>Alanna Miller</b> , Global Policy Lead, RDI	5 mins
18:05-18:10	Video of the rare disease community on the WHA Resolution on Rare Diseases	5 mins
18:10-18:15	Welcome and Introductory Remarks by <b>Dr Kirsten Johnson</b> , Chair, RDI Council	5 mins
18:15-18:30	Keynote Opening Remarks  <b>Dr Rüdiger Krech</b> , Director, Environment, Climate Change and Migration a.i., Division of Health Promotion, Disease Prevention and Care, World Health Organization  <b>H.E. Prof. Khaled Abdel-Ghaffar</b> , Minister of Health and Population, The Arab Republic of Egypt	7 mins  7 mins
18:30-19:55	High-Level Discussion: From Resolution to Transformation  Moderator: <b>Ritu Jain</b> , Secretary, RDI Council  Speakers:  <b>Dr. Jérôme Weinbach</b> , Deputy director, European and International Affairs, Secretariat general – DAEI (Paris), French social ministries  <b>Dr. Adiratna binti Mat Ripen</b> , Head of the Cancer Research Centre, Institute of Medical Research National Institutes of Health of Malaysia	TBC: <b>Brazil, Ghana, Thailand</b>  25 mins
18:55-19:35	Co-creating Equitable Health and Social Systems: Panel discussion with Stakeholders at the Forefront	40 mins

	<p>Moderator: <b>Diego Gil</b>, Council Member, RDI</p> <p>Speakers:</p> <p><b>Kin Ping Tsang</b>, Hong Kong Rare Disease Collaborative Network</p> <p><b>Anne-Sophie Chalandon</b>, International Federation of Pharmaceutical Manufacturers and Associations (IFPMA)</p> <p><b>Ghada Mounib</b>, Forset Hayah Foundation for Rare Diseases</p> <p><b>Claude Meyer</b>, P4H Social Health Protection Network</p>	
19:35-19:42	Remarks from Youth Perspective: <b>Toni Roberts</b> , RDI Youth Leadership Programme (YLP) Member	7 mins
19:42-19:50	Keynote Closing Remarks <b>Dr. Javier Padilla</b> , Secretary of State for Health, Ministry of Health, Kingdom of Spain	8 mins
19:50-20:00	Closing Remarks: <b>Flaminia Macchia</b> , Interim Executive Director, RDI	10 mins