RDI INFORMAL SIDE-EVENT
TO THE 75TH WORLD HEALTH ASSEMBLY (WHA)

MEETING SUMMARY

24 MAY 2022
GENEVA, SWITZERLAND
At the Side-Event “Networking Experts, Centers of Expertise and Patient Organizations to Strengthen Health Systems for Rare Diseases”, RDI explored how national healthcare systems can be strengthened to better support Persons Living With a Rare Disease (PLWRD) and help achieve existing international commitments, including the 2030 Agenda.

The event was a historic moment for the global Rare Disease community, marking the launch of the groundbreaking collaboration between RDI and the WHO toward a Global Rare Diseases Network (GRDN), which will connect experts and expert centers around the world to provide high-quality care to PLWRD.

The WHO affirmed the need to prioritize PLWRD to achieve Universal Health Coverage (UHC), highlighting its commitment to ensuring equitable access to care and quality health services for all.

Recognizing the significant effort made by RDI and the rare disease community over the last years, Rüdiger Krech, endorsed the development of a global network.

“We at the World Health Organization are on your side.” Dr. Rüdiger Krech, WHO Director of Health Promotion, giving the Keynote Address at RDI’s Informal Policy Side-Event to the 75th WHA.
# FULL PROGRAMME

## Opening & Keynote

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<td>18:30-18:40</td>
<td>Opening Remarks</td>
<td>Ms. Durhane Wong-Rieger, Council Chair RDI</td>
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<td>18:40-18:50</td>
<td>Keynote Address</td>
<td>Dr. Rüdiger Krech, Director, Health Promotion Department, WHO</td>
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## 18:50-19:00
- Operational Description of Rare Diseases
  - Dr. Mary Wang, Science Policy Manager, RDI

## 19:00-19:10
- 5 Proposals on Global Networking to Strengthen Health Systems for PLWRD
  - Ms. Flaminia Macchia, Executive Director, RDI

## 19:10-19:25
- Operational Framework for a Global Rare Diseases Network (GRDN)
  - Mr. Matt Bolz-Johnson, Programme Director RDI

## 19:25-19:35
- Equitable Engagement and Community Readiness
  - Dr. Louise Clement, Executive Director, Clinical Partnerships and Education Accreditation, HSO

## 19:35-20:15

### Panel Discussion on the Value of Networked Care Globally

#### Perspective from Patient Groups
- Mr. Salman Saif, CureforU
- Ms. Lisa Sarfaty, National Organization for Rare Disorders, USA

#### Perspective from a Hospital Manager
- Mr. Per Joergensen, Deputy Chief Executive, Rigshospitalet, Copenhagen University Hospital

#### Perspective from Clinical Experts
- Professor Gareth Baynam, Program Director, Undiagnosed Diseases Program-Western Australia
- Professor Carmencita Padilla, Chancellor, University of the Philippines Manila
- Professor Johnny Mahlangu, University of the Witwatersrand, South Africa

## Final Address & Closing

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<td>20:15-20:20</td>
<td>Final Address: Cross-regional Collaboration to Support Health Equity</td>
<td>Mr. Martin Seychell, Deputy Director General at DG INTPA, European Commission</td>
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<td>20:20-20:30</td>
<td>Closing Remarks &amp; Take-home Messages</td>
<td>Mr. Yann Le Cam, Chief Executive Officer, EURORDIS</td>
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Knowledge exchange between centers of excellence and experts within a global network to enable the pooling of knowledge on rare diseases.

1. **Innovative Technology** - Using eHealth and mHealth to accelerate diagnosis and facilitate access to expertise and care.

"What do we want to see in the Global Network? A Network of experts from all around the world who work closely together to increase accessibility and quality of care for PLWRD." Dr. Rüdiger Krech, WHO Director of Health Promotion

2. **Collaboration with WHO**

The event put a spotlight on RDI’s collaboration with the WHO, formalized in 2019 with a Memorandum of Understanding, and detailed annual work plans, the third of which was recently finalized.

With the WHO and all relevant stakeholders, RDI works towards the following long term goals:

- **Increase awareness of rare diseases** and their visibility in healthcare systems.
- **Strengthen healthcare systems**, including improving access to accurate diagnosis, prevention of comorbidity, and promotion of multidisciplinary holistic care.
- **Encourage Member States** to adopt strategies to address rare diseases at national level within an international policy framework.
- **Improve access** to affordable and quality treatments and care.

The current Annual Work Plan focuses on performing an Impact Analysis of the Operational Description of Rare Diseases, working towards the launch of the first Pilot Phase of the Global Rare Diseases Network, and improving access to treatments and care for rare diseases through the Essential Medicines List (EML) and the Essential in Vitro Diagnostics List (EDL).

For more information, please check our website page on Health Equity and Access.
The Operational Description of Rare Diseases aims to provide a common reference to improve the recognition of rare diseases within health systems and support the development of policies that address the challenges faced by Persons Living with a Rare Disease.

To date, there is no internationally recognized definition or description of rare diseases, and national definitions vary greatly from one country to another. RDI and a global Panel of Experts (18 experts from 6 continents) worked together over 5 months to formulate the reference description, composed of a Core Definition and a Descriptive Framework.

“To read the proposed definition, please check our website page on Operational Description of Rare Diseases.”

RDI presented its 5 Proposals showing how global networking can aid in achieving UHC as part of the 2030 Agenda and other international commitments.

Following a survey sent to over 200 persons in the Panel of Experts, the proposals were formulated in collaboration with a working group of 40 members from the Panel of Experts and the RDI Advocacy Committee.

To read the proposed definition, please check our website page on Operational Description of Rare Diseases.

“The 5 Proposals are:

1. Raising Awareness for Rare Diseases.
2. Developing National Plans and Strategies.
3. Creating Networks.
4. Supporting Multi-Disciplinary Care.
5. Supporting and investing in specialized services and centers of expertise.

“We need to facilitate access to expertise and access to diagnosis for the 300 million Persons Living with a Rare Disease to truly leave no one behind.”
Persons Living with a Rare Diseases require a high degree of integrated and networked care. In such a network, experts would be located in multiple healthcare organizations, and highly specialized teams may be based in different countries.

The United Nations Resolution on “Addressing the Challenges of Persons Living with a Rare Disease and their Families” specifically encourages the creation of networks and the strengthening of international collaboration in the field of rare and undiagnosed diseases.

“Clinical networks for rare diseases are not a luxury, but they are a must- have for our community to get the care they need. They are born out of necessity, because the complexity of diseases requires a network of expert knowledge: A Global Rare Disease Network.”

For more information, please check our website page on Global Rare Diseases Network (GRDN).

THE PANEL

To date over 220 experts have been engaged by RDI in developing the Concept Model of the Global Rare Diseases Network.

At the event, 6 expert panelists from Australia, Demark, Pakistan, South Africa, the Philippines and the USA discussed the value of networked care globally.
A TRULY GLOBAL COMMUNITY

We would like to thank the global rare disease community for its incredible support before, during and after the event.

+490 REGISTRATIONS to attend in Geneva and Online

+80 COUNTRIES

ONLINE COMMUNITY

218 ATTENDEES connected live to the digital platform

+600 VIEWS of the event recording within two weeks of the event
Watch the Full Event Recording

REPLAY
NETWORKING EXPERTS, CENTERS OF EXPERTISE AND PATIENT ORGANIZATIONS TO STRENGTHEN HEALTH SYSTEMS FOR RARE DISEASES