STRENGTHENING CARE SYSTEMS FOR PLWRD: THE GLOBAL COMMUNITY IN ACTION

UHCDAY 2021
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Member States need to consider the **three dimensions of coverage when moving toward Universal Health Coverage**: in terms of population, in terms of services, and in terms of proportion of costs covered.

Rare Diseases in the UHC Political Declaration: 34. Strengthen efforts to address (...) rare diseases (...), as part of universal health coverage;
**UHC: WHY IS IT IMPORTANT?**

UHC overarching paradigm for reforming and strengthening health systems in this decade → 2030

**Opportunities to advance the interests of the rare disease community**
- Encourage adoption of RD-specific policies
- Leverage non-specific RD policies that have a positive impact for RD (access to diagnostics and treatments, integrated patient-centred care, research and innovation, digital health, disability)

**UHC and RD policy are mutually reinforcing**
- “Leave no one Behind” - Not Universal if does not include Rare Diseases
- Targeted national policies for RDs contribute to Governments’ efforts towards UHC
STRENGTHENING CARE SYSTEMS TO ACHIEVE EQUITY

UHC requires measures that strengthen healthcare systems in a way that contributes to ensuring Health Equity → reducing inequalities and facilitating equal opportunity to attain the greatest level of health and well-being for all persons, including the most vulnerable populations such as PLWRD.

Especially in a situation where COVID has exacerbated all existing inequalities and vulnerabilities, Building Back Better and inclusive societies for all persons means “Leave No One - Living with a Rare Disease - Behind”.

KEY MESSAGE FROM THE GLOBAL COMMUNITY OF PLWRD:
Health Coverage to be truly Universal needs to focus on Equity. Measures towards achieving UHC should be responsive to diverse realities and multiple forms of inequalities that are different across countries and evolve throughout a lifetime Living with a Rare Disease.
1. RDI IN A NUTSHELL
The Global Alliance of Persons Living with a Rare Disease across all countries and across all rare diseases
VISION, MISSION, OBJECTIVES

VISION
A world where Persons Living with a Rare Disease and their families experience a BETTER LIFE through full recognition and support.

MISSION
A STRONG COMMON VOICE for Persons Living With a Rare Disease and their families around the world.

OBJECTIVES
- To ADVOCATE for rare diseases as an international policy priority through awareness raising, policy promotion and international collaborations
- To REPRESENT Persons Living With a Rare Disease and their families at international institutions and fora
- To SUPPORT the empowerment of RDI members to advocate at national and regional levels
Active in over 100 COUNTRIES covering 6 continents

81 MEMBER ORGANISATIONS

3 RD REGIONAL ALLIANCES
EURORDIS, ALIBER, APARDO

41 NATIONAL ALLIANCES

29 INTERNATIONAL FEDERATIONS

8 MULTI-STAKEHOLDER PLATFORMS
Associate Members
OUR STORY SO FAR

2015
RDI is initiated by EURORDIS & National Alliances in the USA, Canada, Japan, Australia and Russia

2016 & 2019
RDI organizes High Level Meetings at the UN in New York

September 2019
UN includes RDs in Political Declaration on Universal Health Coverage
RDI joins UHC2030 civil society platform

December 2019
RDI and WHO Memorandum of Understanding

June 2020
Common statement on COVID-19

December 2021
Adoption of the UNGA Resolution
2. UNIVERSAL HEALTH COVERAGE
UN POLITICAL DECLARATION ON UHC

December 2018
RDI present at Friends of UHC event at UN HQ

February 2019
RDI Policy Event at the UN: launch a call for the integration of RDs in the UHC Political Declaration

April 2019
Position paper: Leaving No One Behind in UHC with case studies from RDI members

May 2019
RDI hosts Side-Event at the World Health Assembly on UHC

2019
Campaign with National Alliance Ministries of Health, Foreign Affairs & UN PMs

September 2019
UN Political Declaration that includes Rare Diseases

December 2019
Join UHC2030 civil society platform

In October 2020
#UHC4RareDisease Campaign to empower National Alliances to advance UHC policies
#UHC4RareDiseases Toolkit

**FACT SHEET on UHC and rare diseases + 8 languages**
Arabic, Mandarin, French, Hindi, Japanese, Portuguese, Malay, and Spanish

**LETTER TEMPLATE to send to policymakers / MPs / National Health Ministries**

**BRIEFING PACKAGE**

**SOCIAL MEDIA KIT**
#UHC4RareDiseases CAMPAIGN developed to support patient organisations to advocate for RD included in national policies for UHC

#UHC4RareDiseases
- Disseminate the toolkit with additional translated tools;
- Promote UHC in Regional and International Conferences;
- Support National Alliances to reach out to MoH and MoFA

13 DECEMBER 2021: UHC DAY EVENT ON STRENGTHENING CARE SYSTEMS TO ACHIEVE EQUITY

Leverage RDI MEMBERSHIP IN UHC2030 – Resolution4Rare Toolkit is in UHC2030 2021 toolkit

Raise awareness of the contribution of the CGN4RD TOWARDS UHC and strengthening of healthcare systems.
3. INTERNATIONAL ADVOCACY
INTERNATIONAL ADVOCACY AREAS

1. AGENDA 2030
   Advocate for PLWRD within relevant SDGs
   UN Resolution

2. UNIVERSAL HEALTH COVERAGE
   Support PAGs to advocate for national implementation
   1. UN General Assembly
   2. WHO

3. HUMAN RIGHTS
   Promote policies for full inclusion and participation of PLWRD in society
   OHCHR
   Human Rights Council
UNGA RESOLUTION
A CONTRIBUTION TOWARDS AGENDA 2030 AND UHC

• The motto “Leave No One Behind”, at the core of the UN Agenda 2030 Sustainable Development Goals and of the Universal Health Coverage Declaration, is fit for purpose for persons living with a rare disease

• Their challenges need to be addressed in order to meet these SDGs:
UN RESOLUTION AND UHC

**Strengthen health systems** and accelerate achievement of UHC by 2030 for PLWRD and realize their right to physical & mental health and enhance health equity.

Encourage creation of **networks of experts and multidisciplinary specialized centres**

**Support research** by strengthening international collaboration, coordination of research efforts and sharing of data.

Encourage promotion of **mental health & psychological support** for PLWRD, well-being of families & caregivers.
PROMOTING RARE DISEASES AS AN INTERNATIONAL POLICY PRIORITY

Advocacy timeline to integrate rare diseases in the UN System

2019
Making RDs visible in the UN System
High-Level Policy Events at the UN

2020
UN General Assembly Resolution

2021
Follow-up on the UN Resolution with UN Agencies for the integration and appropriation of the RDs Agenda

2022
Work on the implementation of the UN Political Declaration on UHC and the UNGA Resolution at national level

2023
OPPORTUNITIES FOR IMPLEMENTATION

Leaving no one behind: a commitment to equity, non-discrimination and a human rights based approach

- Mobilise human rights bodies at national, regional and international level
- Work with the Office of the High Commissioner for Human Rights (OHCHR)
- Human Right Council Resolution?
OPPORTUNITIES FOR IMPLEMENTATION

- Collaborative clinical networks (ERNs, CGN4RD)
- Continue to engage with WHO
- World Health Assembly Resolution?
OPPORTUNITIES FOR IMPLEMENTATION

Continue advocacy for national plans, policies and initiatives for the benefit of PLWRD with the backing of the UN Resolution
OPPORTUNITIES FOR IMPLEMENTATION

Work with UNICEF for Quality Education and Children’s Rights

Work with UN Women for Gender Equality

Work with the World Bank for a Global Fund for Rare Diseases
4. GLOBAL INITIATIVES
GLOBAL INITIATIVES

- GLOBAL STATE OF THE ART RESOURCE
- CGN4RD
- OPERATIONAL DEFINITION
- GLOBAL ACCESS WG
- WHO ESSENTIAL LISTS

- HEALTH EQUITY & ACCESS

- DIAGNOSIS
- GLOBAL COMMISSION TO END THE DIAGNOSTIC ODYSSEY FOR CHILDREN LWRD
- NEWBORN SCREENING

- PATIENT INVOLVEMENT IN RESEARCH
- IRDiRC PACC
- ICH
HEALTH EQUITY

- Support policy frameworks that promote health equity and improve access to care for PLWRD around the world
- Engage with the WHO and other stakeholders – RDI & WHO signed in 2019 a Memorandum of Understanding

1. **Operational Description of RDs and key prevalence / incidence figures** to inform WHO and Member States

2. **Collaborative Global Network for Rare Diseases (CGN4RD)** to strengthen Healthcare Systems and improve the organization of health and social care services

3. To support inclusion of more in vitro diagnostics and medicines for RD in the **WHO Essential Lists**
COLLABORATIVE GLOBAL NETWORK

Global collaboration engaging the WHO to ensure equitable access to timely diagnosis and care for PLWRD

**Discovery & Development (2020/21):**
- Technical Research
- Needs Assessment Study incl. Concept Model (WHO Deliverables)
- Operational Framework (linked to the terms of reference)
- Support Preparations for the Pilot

**Piloting Phase (2022-24):**
- Call for Application and Assessment
- Pilot WHO Collaborative Global Networks for RD
- Evaluation of the Pilot

**Deployment:**
- Under the WHO Global Programme of Work (GPW14) in 2025-30
- Scale up Global Network and extending Network coverage
- 1st 5-year Cycle of the Network being fully operational

**2020-24**
- **Discovery & Development**
- **Assessment, Pilot & Evaluation**
- **Deployment**
- Fully Operational Network

**2025-29**
- **Evaluation & Renewed Cycle**

**Renewal:**
- Evaluation the Network
- Recommissioning of Network for 2nd 5-year Cycle
1. Develop the Model into an Operational Framework (2021):
   • Governance structure and sustainability model
   • Application and assessment process

2. Preparing for the Pilot (2021-22):
   • Mapping Exercise of Potential Pilot Members
   • Readiness Appraisal of cooperation under Regional Hubs
   • Disease-cluster Working Groups Proposal
   • Digital, data and technical requirements for the pilot network
   • Innovative funding models

3. Product WHO Deliverables (2022):
   • Assessment Manual & Toolkit
   • Operational Framework incl. Eligibility Criteria

   • Multi-linguistic Online Workshops
   • Communication & Advocacy Toolkit (incl. Consultation Book)
   • Support engagement at a National & Regional level
   • Strengthening Healthcare Systems Recommendations
   • Capacity Building - Peer2Peer Webinar Programme

5. Preparation of Applications (2022-23):
   • Support RD Community to develop applications for the Pilot

DEVELOPMENT 2021-23
THANK YOU