



Leveraging Universal Health Coverage to Advance Rare Disease Policy



Celebrating the inclusion of rare diseases in landmark
United Nations Political Declaration on UHC



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WHAT is Universal Health Coverage?

WHO: Universal Health Coverage means:

- Everyone receives quality health services needed...**without financial hardship**
- Includes promotion, prevention, rehabilitation and palliative care and treatment
- Access to essential, safe, affordable, effective and quality **medicines** and **vaccines**

UHC at systems level means:

- **Health systems**:...accountable, integrated, community-based, **people-centred**...competent health workforce, adequate health infrastructure, ...legislative and regulatory frameworks, ...**sufficient and sustainable funding**
- **Equity**, social justice...**elimination...of discrimination and stigma**



Poll One – UHC

Please delete poll questions and responses before presentation.

1

The status of Universal Health Coverage and Rare Diseases in my country is ...

- GOOD UHC for Common Conditions and Same for Rare Diseases
- GOOD UHC for Common Conditions but **NOT Same for Rare Diseases**
- MODERATE UHC for Common Conditions and Same for Rare Diseases
- MODERATE UHC for Common Conditions but **NOT Same for Rare Diseases**
- LIMITED/POOR UHC for Common Conditions and Same for Rare Diseases
- LIMITED/POOR UHC for Common Conditions and **LESS/WORSE for Rare Diseases**
- Don't Know/Not Sure



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Why UN Declaration on UHC? Why Rare Disease?

- UN Political Declaration on UHC commits Governments to:
 - Embrace Aim of universal health coverage for all by 2030
 - Halt rising out-of-pocket health expenditures by providing greater financial risk protection
 - Fit UHC to specific national needs, while increasing outlays for stronger health systems
 - Use all levels of policymaking, governments...multilateral system and existing agreements,
- UN Declaration commits countries to at-risk/underserved groups (8/19)
 - **Strengthen efforts to address...rare diseases and neglected tropical diseases**
 - Increase access to health services for all **persons with disabilities...**

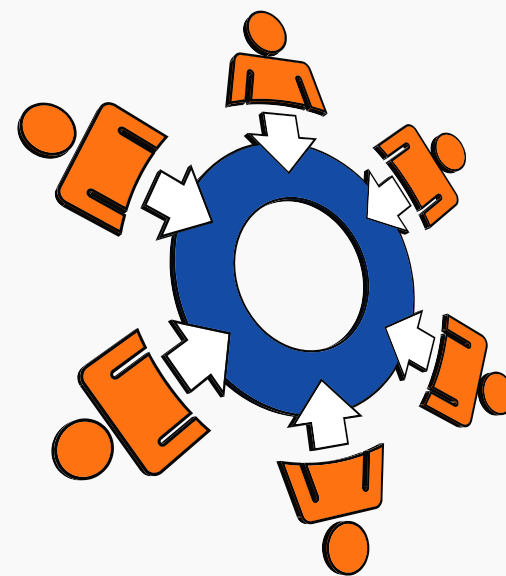
● ***“Leave no one Behind”***



Odyssey: Include Rare Disease in UHC

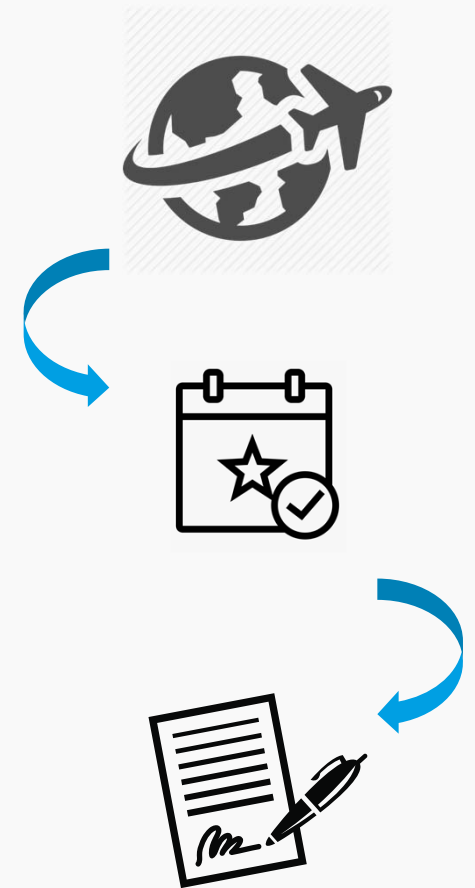
Engage Supporters

- **Top-down:** UN officials, Heads of State, WHO officials, State Permanent Missions
- **Bottom-up:** Patient Advocacy Organizations, RD patient advocates, Friends of UHC
- **Aligned Interests:** Intl Disabilities Alliance, Human Rights Council, NGO Committee(s)
- **Mutual interests:** NCD Alliance, IFPMA, Médecins sans Frontières, LGBTQ(I), Institute for Aging



Odyssey: Roadmap to Rare Disease and UHC

- Learn from others who travelled before
 - International Disabilities Alliance, UNAIDS, NCD Alliance
- Create/leverage opportunities (events)
 - NGO Committee for Rare Diseases (Launch 2016)
 - Int'l UHC Day @UN (Dec 2018)
 - Rare Disease Day @UN (Feb 2019)
 - World Health Assembly Side Event (May 2019)
- End goal: “Rare disease in UN UHC Declaration” (Sep 2019)



Aligned Forerunners on RD & UHC

“No country can claim... universal healthcare if...not...met the needs of those with rare diseases”

- Helen Clark, UNDP
October 2016



“Rare disease patients are a particularly vulnerable group...”

- Rüdiger Krech
WHO, Director of UHC
and Health Systems
May 2018



“WHO’s top priority is ...towards universal health coverage.... This includes access to diagnosis and treatment for people who suffer from rare diseases.”

- Dr Tedros Adhanom Ghebreyesus,
WHO Director General, February 2018



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High-Level Officials: UN and Member States

“...exclusion of rare diseases...is a violation of the right to health...UHC [needs to ensure rare diseases are covered...”

- Andrew Gilmour, ASG Human Rights/Head, High Commissioner for Human Rights, New York



“...will not have achieved UHC unless ...persons with rare diseases are NOT LEFT BEHIND.”

- H.E. Toshiya Hoshino, Ambassador, Deputy, Permanent Mission of Japan to UN



“...access to quality health services and medicines ...especially ...most in need, ...includes people living with rare diseases.”

- H.E. Vitavas Srivihok, Ambassador and Permanent Mission of Thailand to UN (Co-Facilitator UHC)



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Empower RD Patient Community to Advocate UHC

- RDI Position Paper: Rare Diseases: Leaving no one behind in UHC (April 2019)
- RDI & EURORDIS: Empowering National Alliances (Q 2&3, 2019)
 - Toolkit for Advocacy w/Ministries of Health and Foreign Affairs, UN Permanent Missions
 - 13 National Alliances engaged: Argentina, Austria, China, Colombia, Germany, Greece, India, Luxembourg, Malaysia, New Zealand, Romania, Serbia, Spain.



Milestones in Odyssey to Rare Disease & UHC

Council on Convention on Rights of Persons with Disabilities—Oral Statement on needs of persons with disabling rare diseases

June 2018

Report UN Special Rapporteur on Rights of Persons with Disabilities—Rare diseases need specific targeted policies and practices

September 2018



RDI-NGO Rare Disease Day policy event at UN



February 2019

UN Declaration on Universal Health Coverage



Seventy-fourth session
Agenda item 126
Global health and foreign policy

Resolution adopted by the General Assembly on 10 October 2019

[without reference to a Main Committee (A/74/L.4)]
74/2. Political declaration of the high-level meeting on universal health coverage

“Strengthen efforts to address rare disease”

September 2019



Nov 2018

NGO COMMITTEE FOR RARE DISEASES



December 2018

Int'l UH Day—Oral presentation on inclusion of rare diseases as priority



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February 2019

WHA Side Event—Rare Disease & UHC



October 2019

uhc2030






RDI becomes member of the global movement to build stronger health systems for universal health coverage

Poll Two – UHC

Please delete poll questions and responses before presentation.

2

Inclusion of “rare disease” in UN Declaration on Universal Health Coverage helps me advocate more effectively for rare disease services and policy ...

-  Strongly agree
-  Agree
-  Neither agree nor disagree
-  Disagree
-  Strongly disagree



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How can Global Policies increase RDI members' leverage?



1

A “Bill of Rights” to make global policies (UHC, Access to Medicines, disabilities, SDG) accessible and relevant to local PAGs, patients and public

2

Use multiple media methods to raise awareness across all stakeholders of rare disease as identified vulnerable/priority group in UN Declaration on Universal Health Coverage

3

Align with “rights-based” groups on joint initiatives to improve identification, treatment, preventive services, rehabilitation, and supportive care, especially for “marginalized” groups.

4

Invite local and regional WHO representatives to local educational, training, and planning activities

5

Include other populations in rare disease actions; human rights is not a limited good

RDI increase impact through UHC2030

The logo for UHC2030, featuring the letters 'UHC' in a stylized, multi-colored font (blue, green, yellow) and the year '2030' in a simple grey font.

The global movement to build stronger health systems for universal health coverage

Secretariat is led by the WHO and the World Bank



Key Ask 1:
Ensure political leadership beyond health



Key Ask 2:
Leave no one behind



Key Ask 3:
Legislate and regulate



Key Ask 4:
Uphold quality of care



Key Ask 5:
Invest more, invest better



Key Ask 6:
Move together



Across the Key Asks: Commit to gender equality and women's and girls' rights



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Challenge of Emergencies to UHC

- UN Pre-sage: Increasing number of **complex emergencies** hinder UHC
 - [Need] Coherent and inclusive approaches to safeguard UHC in emergencies
 - Ensur[e] continuum and provision of essential health services and public health function



Faced by the COVID-19 crisis, it is crucial that world leaders remember their universal health coverage commitments

26th March 2020

- WHO Coronavirus Guidance: Maintaining Essential Health Services
 - Countries will need to make difficult decisions to balance the demands of responding directly to COVID-19, while simultaneously engaging in strategic planning and coordinated action to maintain essential health service delivery, mitigating the risk of system collapse.








Poll Three – UHC

Please delete poll questions and responses before presentation.



I would be interested in having tools and training on how to leverage UHC to advocate for rare disease.

-  Strongly agree
-  Agree
-  Neither agree nor disagree
-  Disagree
-  Strongly disagree



Questions?

