



# Rare Diseases:

## Leaving no one behind in Universal Health Coverage

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**We must work together to ensure an equitable and affordable access to quality health services and medicines for everyone, especially people who are most in need, which also includes people living with rare diseases, while ensuring that they do not face financial hardship or fall back into poverty because of their catastrophic medical expenses. This is in line with our commitment in the 2030 Agenda to leave no one behind. Millions of people around the world are suffering from rare diseases, which require some of the most advanced and expensive forms of treatment and interventions. As a result, these people and their families carry very high burden in many aspects of life – physically, financially and socially.**



H.E. Vitavas Srivihok,  
Ambassador and Permanent Representative,  
Permanent Mission of Thailand to the UN,  
Co-Facilitator for the Negotiation of the Political  
Declaration of the High-Level Meeting on UHC  
21 February 2019

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**WHO's top priority is to support countries on the path towards universal health coverage, with the aim of ensuring that all people can access the health services they need. [...] This includes access to diagnosis and treatment for people who suffer from rare diseases.**



Dr Tedros Adhanom Ghebreyesus, WHO  
28 February 2018

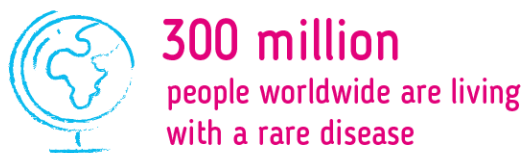
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## Executive Summary

The December 2017 UN General Assembly Resolution on Global Health and Foreign Policy sets forth two very important principles. On the one hand, it affirms the need to address the health of the most vulnerable for an inclusive society – hence acknowledging that the health of the most vulnerable is both a core component and a condition of an inclusive society. On the other hand, it spells out the importance of placing *"a specific emphasis on the [...] vulnerable and marginalised segments of the population"* (art. 6) at the heart of any strategy to progress towards the goal of universal health coverage.

In so doing, the Resolution furthers the spirit of the 1948 Universal Declaration of Human Rights and of the UN Conventions on the Rights of the Child (1989) and on the Rights of Persons with Disabilities (2006).

**These principles matter to the highest point for the global community of people living with rare diseases, as we count amongst the most vulnerable and marginalised populations on the planet today.**



**Rare diseases consist of well over 6,000 conditions**, often of genetic origin, which affect small to ultra-small populations of patients (typically fewer than 1 in 2,000 individuals). Most rare diseases are complex, chronic, degenerative, disabling and frequently life-threatening. They lead to serious unmet needs for the persons affected, their families and their caregivers, ranging from health and quality of life to equality, social inclusion, access to education, but also access to employment and other opportunities to give back to society and be an active member of it.

When considered as a whole, rare diseases affect an estimated 4 percent of the world's population, thus **about 300 million people worldwide at the very least** – a figure on par with other major non-communicable diseases. Despite this, rare diseases are all too often neglected, to a large extent because of insufficient medical knowledge, which in turn puts a barrier to timely diagnosis, to the recognition of associated disabilities and symptoms, and to the access of affected individuals to the support they need, be it financial, educational or social. Ultimately, this effectively bars persons living with rare diseases from genuine integration into society and, consequently, from achieving the *"realization [...] of the economic, social and cultural rights indispensable for [their] dignity and the free development of [their] personality"* (art. 22 of the December 1948 Universal Declaration of Human Rights).



*A rare disease affects...*



HEALTH



FAMILY



EDUCATION



WORK



ECONOMY



SOCIETY



SCIENCE

Rare diseases have until today rarely been discussed in connection with the ongoing political conversation on universal health coverage. However, we firmly believe – as the 2017 Resolution itself notes – that rare diseases fully belong in that debate, not least as the essence of the aspirations and objectives behind universal health coverage resonate immensely with the daily experience, needs and expectations of all persons living with a rare disease across the world.

**We, as the global rare diseases movement borne out of civil society more than 40 years ago, are calling for rare diseases to be understood and recognised as the “missing pillar” in the current reflections on, and models of, universal health coverage.**

**Rare diseases lead to a strong impact on work-life balance for rare disease patients  
– absence from work, hampered professional activity and economic burden.**

**70%** of patients  
& carers

reduced or stopped  
professional activity due  
to their or their family  
member's rare disease



**58%**

are absent from work  
over 15 days per year



**69%**

face a decrease  
in income



This position paper presents our views that:

- › The global rare diseases and universal health coverage movements share a profound commonality of spirit and vision, grounded in the universality principle, the emphasis on individuals receiving the right health services without hardship, the strive towards a holistic and integrated approach to health, and the focus on human rights, equity, solidarity and social justice.
- › Universal health coverage shall never be fully attained nor realised if persons living with rare diseases are left behind and their needs left unmet. The major theories of social justice at the origin of the notion of universal health coverage all recognise the importance of a substantial focus



on the most vulnerable and neglected communities in society, and leave no doubt that the true benchmark of how inclusive a society is is how it addresses the health of its most vulnerable.

- › **The objection that universal health coverage approaches should focus on the needs of the many rather than those of the few is a fallacy.** Even in resource-constrained settings, it is possible and even necessary to prioritise rare diseases at the earliest stages of planning for universal health coverage.
- › **The time to integrate rare diseases in the reflection on, and practice of, universal health coverage is now.** The decision to stand up for the needs of vulnerable minority groups ultimately remains a political responsibility and a societal choice. And far from being an impossible one to make, we feel encouraged by the examples of many countries or even regions across the world that have clearly understood the structural importance of rare diseases in a universal health coverage context, and reflected it in new multi-sectorial policies and legislation to address the comprehensive needs of people living with rare diseases – **in highly developed countries like in less developed nations.**

Throughout the world, civil society is, and will continue to be, a leading partner to catalyse the transition of existing healthcare systems towards universal health coverage models. The global rare diseases movement is ready today to take its rightful place amongst other components of international civil society to support and accomplish that ambition. Across the world, our community has decades of medical knowledge, patient education campaigns and a wealth of other resources that are waiting to be put to good use to make universal health coverage not just a reality, but a success for all.

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The global rare diseases movement looks forward to contributing to the **Political Declaration on Universal Health Coverage** and to sharing our experience at the **23 September 2019 UN High-Level Meeting on Universal Health Coverage in New York**.

**We are impatient to demonstrate our readiness to « *move together to build a healthier world* »,** one in which the more than 300 million people living with a rare disease worldwide will feel at long last more widely recognised, better supported and fully associated to one of the most inspiring endeavours of this century.

**We hereby call on all partners – UN agencies, NGOs but also the Group of Friends of UHC and all other national governments – to join us in constructive exchanges to explore and advance our current proposals and, where possible, to ideate new ones together.**

**This common journey must begin now.**

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**International Universal Health Coverage Day  
12 December 2018, United Nations Headquarters, New York**

RDI was invited to participate in a Discussion Panel organised by WHO and Group of Friends of UHC (Japan, Brazil, France, Ghana, Hungary, South Africa, Thailand) at United Nations in New York. RDI was the only civil society organisation represented in the panel.

Durhane Wong-Rieger, Chair of the Council of RDI addressed dignitaries and delegates.



## Foreword: Firming up the Contours of Universal Health Coverage

Since 2005 and its first ever appearance in an official political statement from the United Nations<sup>1 2</sup>, the concept of universal health coverage has become "*an increasingly central rallying point for global health advocacy*"<sup>3</sup>. In parallel, the concept has also undergone over the years a number of evolutions and refinements – not least to limit the profusion of diverse and sometimes disconnected definitions and, in turn, to help bring greater unity to its denomination, scope and ambition<sup>4</sup>.

For the present paper, we decided to take as a central point of reference the latest definition proposed and publicised by the World Health Organisation itself, i.e.:

*« Universal health coverage means that **all individuals and communities receive the health services they need without suffering financial hardship.***

*It includes the full spectrum of essential, quality health services, **from health promotion to prevention, treatment, rehabilitation, and palliative care.***

***Universal health coverage enables everyone to access the services that address the most important causes of disease and death, and ensures that the quality of those services is good enough to improve the health of the people who receive them.***

*[...] Universal health coverage is not just about health financing. **It encompasses all components of the health system:** health service delivery systems, the health workforce, health facilities and communications networks, health technologies, information systems, quality assurance mechanisms, and governance and legislation.*

*Universal health coverage is not only about ensuring a minimum package of health services, but also about ensuring a progressive expansion of coverage of health services and financial protection as more resources become available.*



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<sup>1</sup> World Health Assembly Resolution WHA58.33 on "Sustainable health financing, universal coverage and social health insurance", May 2005  
Accessible here > [apps.who.int/iris/bitstream/handle/10665/20383/WHA58\\_33-en.pdf;jsessionid=4320AC182F1575E1B66F9D0660D9C24D?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/20383/WHA58_33-en.pdf;jsessionid=4320AC182F1575E1B66F9D0660D9C24D?sequence=1)

<sup>2</sup> While we refer herein to the May 2005 World Health Assembly Resolution as a milestone political statement and a generally acknowledged starting point for the contemporary concept of universal health coverage, it is only fair to also note that the concept can actually be traced back much earlier in time. It is for instance present in germ form in paragraph 6 of the final declaration of the September 1978 International Conference on Primary Health Care in Alma-Ata, USSR, which reads: "*primary health care is essential health care [...] made universally accessible to individuals and families in the community [...] at a cost that the community and country can afford*". See here > [www.who.int/publications/almaata\\_declaration\\_en.pdf](https://www.who.int/publications/almaata_declaration_en.pdf) The aspirations and commitments of the 1978 Alma-Ata Declaration were most recently reaffirmed at the Global Conference on Primary Health Care in October 2018 in Astana and in the ensuing Declaration, accessible here > [www.who.int/publications/almaata\\_declaration\\_en.pdf](https://www.who.int/publications/almaata_declaration_en.pdf)

<sup>3</sup> "The evolution of the field of Health Policy and Systems Research and outstanding challenges", Bennett et al. Health Research Policy and Systems (2018) 16:43. Accessible here > [www.ncbi.nlm.nih.gov/pmc/articles/PMC5966862/pdf/12961\\_2018\\_Article\\_317.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5966862/pdf/12961_2018_Article_317.pdf)

<sup>4</sup> "What does universal health coverage mean?", O'Connell et al. Lancet (2014); 383: 277–79. Accessible here > [www.thelancet.com/pdfs/journals/lancet/PIIS0140673613609551.pdf](https://www.thelancet.com/pdfs/journals/lancet/PIIS0140673613609551.pdf)

<sup>5</sup> Health Systems Strengthening for Universal Health Coverage. WHO, accessible here: [http://www.searo.who.int/about/administration\\_structure/hsd/en/](http://www.searo.who.int/about/administration_structure/hsd/en/)



[...] Universal health coverage is comprised of ***much more than just health***; taking steps towards universal health coverage means steps towards ***equity, development priorities, and social inclusion and cohesion***. »<sup>6</sup>

## 1. The Global Rare Diseases Movement and Universal Health Coverage

### A Commonality of Spirit and Vision

#### Summary

The global rare diseases and universal health coverage movements share a profound commonality of spirit and vision, deeply entrenched in the guiding principles and objectives that sustain their respective aspirations, and in the direct continuity of the aspirations set out in the UN Convention on the Rights of the Child (1989) and the UN Convention on the Rights of Persons with Disabilities (2006). The universality principle, the emphasis on individuals receiving the right health services without hardship, the strive towards a holistic and integrated approach to health, or still the permanent focus on “more than just health” and on the human rights, equity, solidarity and social justice dimensions – all represent living bridges fostering a genuine kinship between the ideals of the global rare diseases movement and the WHO’s ambitions for universal health coverage.

#### The Rare Diseases Movement: A Civil Society-Driven Endeavour with Global Aspirations

Rare diseases were coined as a specific issue deserving social interest less than 35 years ago and in different parts of the world simultaneously, from the United States all the way across to Europe and Asia. In each region, representatives of what were very small patient organisations at the time came together with pioneering doctors and geneticists to begin to form a better understanding of the challenges associated with the rarity of a given disease, but also of the conditions required for a broader societal effort towards overcoming these difficulties.<sup>7</sup>



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<sup>6</sup> “Universal health coverage (UHC)”, WHO Fact Sheet, last updated December 2018. Accessible here > [www.who.int/news-room/fact-sheets/detail/universal-health-coverage-\(uhc\)](http://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc))

<sup>7</sup> “How It All Started: The Contribution of the NGO Community to Advancing the Causes of Rare Diseases”, speech by Mr Terkel Andersen, EURORDIS-Rare Diseases Europe, at the Global Gathering for Rare Diseases in New York, 11 November 2016  
Accessible here > [www.ngocommitteerarediseases.org/wp-content/uploads/2017/06/04b-Terkel-Andersen-Speech.pdf](http://www.ngocommitteerarediseases.org/wp-content/uploads/2017/06/04b-Terkel-Andersen-Speech.pdf)

<sup>8</sup> “Report from the Inauguration of the NGO Committee for Rare Diseases”, February 2017. See reference on page 9. Accessible here > [download2.eurordis.org.s3.amazonaws.com/ngocommittee/ngocommittee\\_report.pdf](http://download2.eurordis.org.s3.amazonaws.com/ngocommittee/ngocommittee_report.pdf)



Over time, the rare diseases movement structured itself more decisively – first at the national level, then at the regional level and most recently at the global level. Annual observances like Rare Disease Day<sup>9</sup> (initiated in 2008) but also platforms like the International Rare Diseases Research Consortium<sup>10</sup> (IRDIRC, founded 2011), Rare Diseases International<sup>11</sup> (RDI, founded 2014) or still the NGO Committee for Rare Diseases at the United Nations<sup>12</sup> (founded 2016) have all played a seminal role to make the voices, needs and expectations of the more than 300 million people living with a rare disease worldwide better heard and understood within the UN system but also in the broader concert of nations at large.

Along that journey and at the initiative of each of these platforms, a number of milestone declarations and political statements were adopted by the global rare diseases movement to affirm its identity, beliefs and aspirations. The Yukiwariso Declaration launched by ICORD<sup>13</sup> in Tokyo in 2012, the Joint Declaration on *"Rare Diseases: An International Public Health Priority"* launched by RDI in Madrid in 2015 or still the Founding Act of the NGO Committee for Rare Diseases launched in New York in 2016 all converged to call for a more resolute and better coordinated international collaboration to address the challenges posed by rare diseases.

This trajectory towards heightened global awareness is not fundamentally different in essence from that which saw the concept of universal health coverage come (over many more years, however) to the prominence it enjoys today in international policy circles.

But the most striking similarity between the global rare disease movement and the universal health coverage one is not one of direction or journey – **it is rather one of substance.**

### The Rare Diseases and Universal Health Coverage Movements: Shared Ideals, Shared Goals

In its current definition and remit, the notion of universal health coverage finds its historical source and inspiration in milestone international declarations and treaties such as the 1948 **Universal Declaration of Human Rights**<sup>14</sup>, the 1989 **UN Convention on the Rights of the Child**<sup>15</sup> or still the 2006 **UN Convention on the Rights of Persons with Disabilities**<sup>16</sup>. The provisions pertaining to health in each of these documents are not only forming the bedrock of the contemporary theory of universal health coverage – they are also of utmost and very direct relevance for the global community of people living with rare diseases as they define at the highest possible level the fundamental rights that our community can legitimately aspire to enjoy:

<sup>9</sup> [www.rarediseaseday.org](http://www.rarediseaseday.org)

<sup>10</sup> [www.irdirc.org](http://www.irdirc.org)

<sup>11</sup> [www.rarediseasesinternational.org](http://www.rarediseasesinternational.org)

<sup>12</sup> [www.ngocommitteerarediseases.org](http://www.ngocommitteerarediseases.org)

<sup>13</sup> [www.icord.se](http://www.icord.se)

<sup>14</sup> [www.un.org/en/universal-declaration-human-rights/](http://www.un.org/en/universal-declaration-human-rights/)

<sup>15</sup> [downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC\\_united\\_nations\\_convention\\_on\\_the\\_rights\\_of\\_the\\_child.pdf?\\_ga=2.192252712.368241948.1554555073-1447676802.1554555073](http://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_ga=2.192252712.368241948.1554555073-1447676802.1554555073)

<sup>16</sup> [www.un.org/disabilities/documents/convention/convoptprot-e.pdf](http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf)





*“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including [...] medical care and necessary social services, and the right to security in the event of [...] sickness, disability [...] or other lack of livelihood in circumstances beyond his control.”*

*1948 Universal Declaration of Human Rights, article 25, paragraph 1*

*“States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.”*

*1989 UN Convention on the Rights of the Child, article 24, paragraph 1*

*“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. In particular, States Parties shall [...] provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, [...] prohibit discrimination against persons with disabilities in the provision of health insurance, [...] prevent discriminatory denial of health care or health services”*

*2006 UN Convention on the Rights of Persons with Disabilities, article 25 (excerpts)*

Even nearer to us, a cross-comparison of the core principles at the heart of the notion of universal health coverage and of the major ideas and messages advocated in the milestone statements issued by the global rare diseases community from 2011 to 2016 reveals a striking level of similarity and alignment:



WHO: Principles of Universal Health Coverage (as per the December 2018 WHO Fact Sheet) <sup>17</sup>	ICORD: Yukiwariso Declaration (2011-2012) <sup>18</sup>	RDI: Joint Declaration (2015) <sup>19</sup>	RDI: International Recommendations to Address Specific Needs of Undiagnosed Rare Disease Patients (2016) <sup>20</sup>	NGO Committee for Rare Diseases: Founding Act (2016) <sup>21</sup>
<b>Universality:</b> "... all individuals and communities receive the health services they need..."	"... the ethical principle of justice requires that the needs of rare disease populations are specifically addressed, as they should be for any minority or underserved community..." (pg. 4)  "... [the] rarity of a disease should not be grounds for denying access to services or therapies..." (pg. 6)	"3. Support and empower patients and families to [shape] national health care provision that is appropriate to their needs"  "7. Facilitate universal access to high quality healthcare and treatments for rare diseases patients [...]"	"... undiagnosed rare disease patients should be recognised as a distinct population with specific unmet needs by national authorities to enable development of personalised health and social care..." (pg. 1)	"... no one country, no one continent alone can solve the problems posed by rare diseases..."
<b>Financial Protection:</b> "... without financial hardship... reduc[ing] the risk that people will be pushed into poverty"	"... rare diseases create disparities and vulnerabilities in health status for affected populations and [governments] should put in place specific policies to address them..." (pg. 6)	"12. Elaborate policies based on common values (equity, solidarity and social justice) that have a positive impact on the lives of rare diseases patients"	"... in most countries, undiagnosed rare disease patients remain an invisible and highly vulnerable population..." (pg. 4)  "... late diagnoses [...] can have irreversible and life-threatening consequences; undiagnosed rare disease patients and families also face added social and daily life challenges..." (pg. 3)	
<b>Holistic Approach to Health:</b> "... the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care..."	"... governments should adopt policies that aim to achieve equitable allocation of resources towards all aspects of rare diseases, incl. research, clinical care, information resources and development of treatments..." (pg. 6)	"1. Enhance visibility of rare diseases [...] in terms of public awareness and within the healthcare system [as] a public health priority"  "6. Improve access to services that will facilitate informed decisions about prevention and screening [...] and improve access to accurate and timely diagnosis"		"... rare diseases fit within the objectives of several UN SDGs (1, 3, 4, 5, 8, 10 and 17) and can significantly contribute to their achievement..."

<sup>17</sup> See footnote 5 above

<sup>18</sup> [icord.se/wp-content/uploads/2012/08/ICORD-Yukiwariso-Declaration-Final-August-2012.pdf](http://icord.se/wp-content/uploads/2012/08/ICORD-Yukiwariso-Declaration-Final-August-2012.pdf)

<sup>19</sup> [download2.eurordis.org.s3.amazonaws.com/rdi/rdi\\_jointdeclaration\\_colour.pdf](http://download2.eurordis.org.s3.amazonaws.com/rdi/rdi_jointdeclaration_colour.pdf)

<sup>20</sup> [download2.eurordis.org.s3.amazonaws.com/documents/pdf/Undiagnosed-International-Joint-Recommendations.pdf](http://download2.eurordis.org.s3.amazonaws.com/documents/pdf/Undiagnosed-International-Joint-Recommendations.pdf)

<sup>21</sup> [www.ngocommitteerarediseases.org/wp-content/uploads/2016/11/NGO-Committee-for-Rare-Diseases-Founding-Act-FINAL.pdf](http://www.ngocommitteerarediseases.org/wp-content/uploads/2016/11/NGO-Committee-for-Rare-Diseases-Founding-Act-FINAL.pdf)



WHO: Principles of Universal Health Coverage (as per the December 2018 WHO Fact Sheet) <sup>17</sup>	ICORD: Yukiwariso Declaration (2011-2012) <sup>18</sup>	RDI: Joint Declaration (2015) <sup>19</sup>	RDI: International Recommendations to Address Specific Needs of Undiagnosed Rare Disease Patients (2016) <sup>20</sup>	NGO Committee for Rare Diseases: Founding Act (2016) <sup>21</sup>
<b>Quality of Care:</b> "... ensur[ing] that the quality of those services is good enough to improve the health of the people who receive them..."	"... responses such as prioritization and the need to ration resources, as reasons for lesser attention to rare diseases [...] are not ethically sustainable arguments..." (pg. 5)	"7. Facilitate universal access to high quality healthcare and treatments for rare diseases patients [...]"	"... to improve outcomes for the 'not yet diagnosed' group, both the route to, and the quality of, diagnostic tools and also access to extensive genomic data need to be improved..." (pg. 2)	
<b>Integrated Healthcare System Thinking:</b> "... not just about health financing. It encompasses all components of the health system: health service delivery systems, the health workforce, health facilities and communications networks, health technologies, information systems, quality assurance mechanisms, and governance and legislation..."	"... governments should adopt policies that aim to achieve equitable allocation of resources towards all aspects of rare diseases, incl. research, clinical care, information resources and development of treatments..." (pg. 6)	"1. Enhance visibility of rare diseases [...] in terms of public awareness and within the healthcare system [as] a public health priority"  "2. Better classification and codification of rare diseases..."  "8. Create policies [...] that promote specific measures in regional / national / international strategies, incl. identification and support of specialised expert providers..."  "11. Build opportunities for effective networking of patient registries"	"... undiagnosed rare disease patients require the availability of a complete health and social care pathway in advance of receiving a diagnosis..." (pg. 2)  "... integrated clinical and social pathways specifically designed to answer [the] needs [of undiagnosed rare disease patients]..." (pg. 4)	"... common national policies and international collaboration can address these challenges..."
<b>Dynamic Approach Over Time:</b> "... not only about ensuring a minimum package of health services, but also about ensuring a progressive expansion of coverage of health services and financial protection as more resources become available..."	"... responses such as prioritization and the need to ration resources, as reasons for lesser attention to rare diseases [...] are not ethically sustainable arguments..." (pg. 5)	"6. Improve access to services that will facilitate informed decisions about prevention and screening [...] and improve access to accurate and timely diagnosis"		
<b>More Than Just Health:</b> "... taking steps towards UHC means steps towards equity, development priorities, and social inclusion and cohesion..."	"health care and treatment for rare diseases is a human rights issue; non-discrimination, justice and equity of access to health care, all require that specific policies are	"12. Elaborate policies based on common values (equity, solidarity and social justice) that have a positive impact on the lives of rare diseases patients"	"... national sustainable programmes dedicated specifically for undiagnosed diseases should be developed [...] to enable rapid and equitable	"... persons living with rare diseases worldwide are facing common challenges across diseases and across borders that affect all parts of their lives..."

WHO: Principles of Universal Health Coverage (as per the December 2018 WHO Fact Sheet) <sup>17</sup>	ICORD: Yukiwariso Declaration (2011-2012) <sup>18</sup>	RDI: Joint Declaration (2015) <sup>19</sup>	RDI: International Recommendations to Address Specific Needs of Undiagnosed Rare Disease Patients (2016) <sup>20</sup>	NGO Committee for Rare Diseases: Founding Act (2016) <sup>21</sup>
	<p><i>put in place to address the needs of people affected by rare diseases..." (pg. 4)</i></p> <p><i>"... a comprehensive approach to rare diseases is needed, incl. education, research, prevention, diagnosis, care and treatment, social support and inclusion..." (pg. 5)</i></p>		<p><i>access to diagnosis and social support..." (pg. 1)</i></p> <p><i>"... undiagnosed rare disease patients and families also face added social and daily life challenges..." (pg. 3)</i></p> <p><i>"... addressing the issues associated with access to social services, education, occupation, and rehabilitation support..." (pg. 3)</i></p>	<p><i>"... rare diseases fit within the objectives of several UN SDGs (1, 3, 4, 5, 8, 10 and 17) and can significantly contribute to their achievement..."</i></p>

**Table 1** · Comparing the core principles at the heart of the concept of universal health coverage with central tenets and messages from major global rare disease statements and declarations (2011-2016)

This succinct comparison highlights several areas of meaningful convergence:

- The **universality** principle whereby all individuals and communities should receive the health services they need is inseparable from the views upheld by the global rare diseases movement, which contends that people living with a rare disease (and even more so, undiagnosed rare disease patients) should be recognised as a distinct community with very specific needs to be met.
- The emphasis placed on **receiving the right health services without hardship** resonates with the general recognition that people living with a rare disease are highly vulnerable and at a greater disadvantage compared to the general population, and that they therefore need specific support underpinned by the principles of equity, solidarity and social justice to protect them from social challenges and poverty. The high level of medical complexity inherent to rare and ultra-rare diseases also goes hand in hand with a greater need to make high-quality healthcare accessible to affected individuals and their families, fully in keeping with the spirit of universal health coverage.
- All of the major statements on rare diseases listed hereabove promote a **holistic and integrated approach to health**, ranging comprehensively all the way from governance to system design, from resource allocation to actual care delivery, or from research to treatment. In that regard, they are well aligned with the currently accepted concept of universal health coverage and supportive of the aspiration not to reduce UHC to health financing merely.
- Above all, the understanding that **universal health coverage is "more than just health"** is sharply mirrored in the views advocated by the global rare diseases movement, which has repeatedly



positioned healthcare for rare diseases as not only a health issue but even more fundamentally one of human rights, equity, solidarity and social justice.

From all this, it appears reasonable and legitimate to conclude that the core principles, messages and demands that have been at the cornerstone of the global rare diseases movement's advocacy and action over the past half-decade bear not just a substantial degree of similarity – *but, even more so, a genuine commonality* – with those heralded by the universal health coverage movement and, before that, by major international declarations of rights.



## 2. No Universal Health Coverage Without Rare Diseases

### An Ethical Imperative Anchored in the Theories of Social Justice

#### Summary

Universal health coverage shall never be fully attained nor realised if persons living with rare diseases are left behind and their needs are not met. The major theories of social justice that deeply underpin the concept and ambition of universal health coverage all recognise the importance of a substantial focus on the most vulnerable and neglected communities in society.

“For me, the key question of universal health coverage is an ethical one. Do we want our fellow citizens to die because they are poor? Or millions of families impoverished by catastrophic health expenditures because they lack financial risk protection? Universal health coverage is a human right.”



Dr Tedros Adhanom Ghebreyesus,  
17 July 2017

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#### Addressing the Needs of the Most Vulnerable: The Hallmark of Truly Universal Health Coverage

Although essential, it is not enough to underline the kindred spirit and shared fundamentals between the universal health coverage and rare diseases movements. The collective reflection on the place of rare diseases in the current and future debate on universal health coverage shall not be complete nor relevant if **the impossibility to fully achieve universal health coverage without a strong emphasis on rare diseases** is not properly understood and, in turn, acted upon by policymakers

“No country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases.”



Helen Clark, UNDP,  
20 October 2016

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<sup>22</sup> “All roads lead to universal health coverage” Adhanom Ghebreyesus T, 17 July 2017. Accessible here > [www.who.int/news-room/commentaries/detail/all-roads-lead-to-universal-health-coverage](http://www.who.int/news-room/commentaries/detail/all-roads-lead-to-universal-health-coverage)

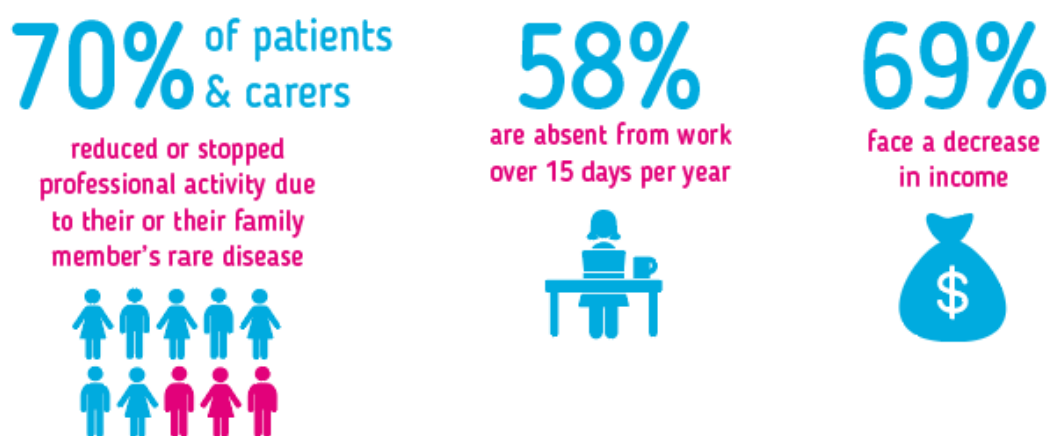
<sup>23</sup> “Helen Clark: Written Statement at the 11th Annual International Conference on Rare Diseases and Orphan Drugs”, 20 October 2016. Accessible here > [www.undp.org/content/undp/en/home/presscentre/speeches/2016/10/20/helen-clark-written-statement-at-the-11th-annual-international-conference-on-rare-diseases-and-orphan-drugs.html](http://www.undp.org/content/undp/en/home/presscentre/speeches/2016/10/20/helen-clark-written-statement-at-the-11th-annual-international-conference-on-rare-diseases-and-orphan-drugs.html)

This was the exact meaning of the address that Helen Clark, former Administrator of the UN Development Programme (UNDP), delivered to the 2016 ICORD Annual Conference in Cape Town, when she noted that *"no country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases"*.

That statement was naturally in line not only with the aspirations of Sustainable Development Goal no. 3, *"ensure healthy lives and promote well-being for all at all ages"*, target 3.8 of which aims to *"achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all"*<sup>24</sup> but also, reaching even farther back in time, with the ambition of *"achieving health for all"* expressed at Alma Ata in 1978.

That statement was also echoed in the provisions of **UN General Assembly Resolution 72/139 from 12 December 2017 on Global Health and Foreign Policy**<sup>25</sup>, several paragraphs of which (as referenced in the following table) leave no ambiguity as to the fact that the needs of the *"poor, vulnerable and marginalised segments of the population"* represent a specific and crucial constituency for any effort or programme aimed at bringing universal health coverage to life.

### Rare diseases lead to a strong impact on work-life balance for rare disease patients - absense from work, hampered professional activity and economic burden.



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<sup>24</sup> [sustainabledevelopment.un.org/sdg3#targets](https://sustainabledevelopment.un.org/sdg3#targets)

<sup>25</sup> "Global health and foreign policy: Addressing the health of the most vulnerable for an inclusive society" Resolution 72/139, adopted by the General Assembly on 12 December 2017. Accessible here > [www.un.org/en/ga/search/view\\_doc.asp?symbol=A/RES/72/139](http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/72/139) Note that the provisions of that Resolution were already sketched as early as 2012 in UN General Assembly Resolution 67/81 (also on "Global Health and Foreign Policy"), which urged Member States to accelerate progress towards universal health coverage, and again in 2015 in UN General Assembly Resolution 70/1 "Transforming our world: the 2030 Agenda for Sustainable Development", which enshrined the target of achieving universal health coverage by 2030, including financial risk protection, access to quality essential healthcare services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

<sup>26</sup> "Juggling care and daily life. The balancing act of the rare disease community. A Rare Barometer Survey" EURORDIS-Rare Diseases Europe, May 2017. Accessible here > [http://download2.eurordis.org.s3.amazonaws.com/rbv/2017\\_05\\_09\\_Social%20survey%20leaflet%20final.pdf](http://download2.eurordis.org.s3.amazonaws.com/rbv/2017_05_09_Social%20survey%20leaflet%20final.pdf)





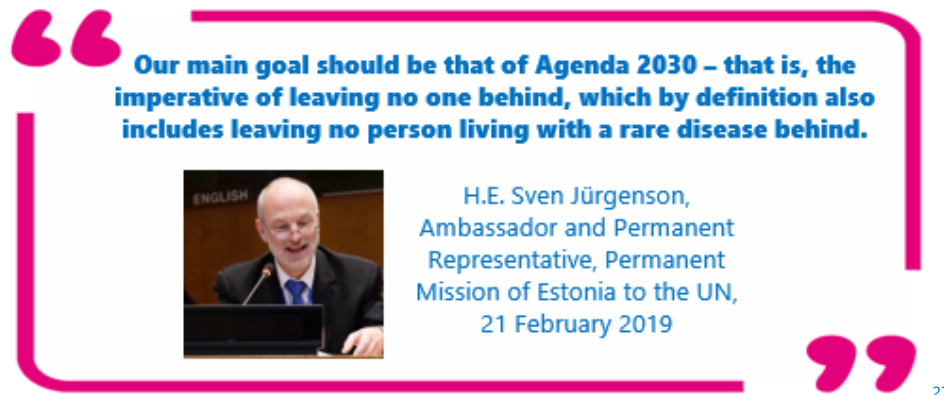
“The General Assembly [...]

6. *Calls upon* Member States to accelerate progress towards **the goal of universal health coverage, which implies that all people have equal access, without discrimination of any kind**, to nationally determined sets of quality promotive, preventive, curative, rehabilitative and palliative basic health services needed and essential, safe, affordable, effective and quality medicines, while ensuring that the use of such services and medicines does not expose the users to financial hardship, **with a specific emphasis on the poor, vulnerable and marginalized segments of the population**;
7. *Encourages* Member States to promote **the effective, full and meaningful participation of all, in particular those who are vulnerable or in vulnerable situations, in the design, implementation and monitoring of law, policies and programmes relevant to realizing the right of everyone to the enjoyment of the highest attainable standard of physical and mental health** and to implementing the health-related Sustainable Development Goals, including strategies for universal health coverage;
8. *Calls upon* the international community and global health partners, as well as regional and national stakeholders, to support Member States in carrying out their primary responsibilities to accelerate the transition towards universal health coverage, and tackle social, economic and environmental determinants of health, as well as demographic challenges, including population ageing, provide social protection and **adopt integrated, people-centred, community-based and gender-responsive health services based on human rights, which will help to empower those who are vulnerable or in vulnerable situations, enhance health equity and equality, end discrimination and create a more inclusive society**;
10. *Encourages* Member States to secure sustainable financing for health research and development on emerging and re-emerging diseases, neglected tropical diseases, non-communicable diseases, including cancers and mental health, and antimicrobials, promote safe, affordable, effective and quality medicines, including antimicrobials and traditional medicines, and vaccines, **enhance access to health products, therapies and medical devices, and promote preventive and treatment interventions and diagnostics for all those in need, in particular for the most vulnerable**;
11. *Calls upon* Member States to **promote and strengthen, as appropriate, their dialogue with other stakeholders, including civil society**, academia and the private sector, in order to maximize their engagement in and contribution to the implementation of health goals and targets through **an intersectoral and multi stakeholder approach [...]** ;
12. *Encourages* the development of innovative and sustainable mechanisms to ensure necessary and sustained health financing and enhance international coordination and **an enabling environment at all levels to strengthen health systems, and promote universal access to quality health services, including through partnerships with civil society** and the private sector [...]

**Table 2** • Relevant excerpts from UN General Assembly Resolution 72/139  
from 12 December 2017 on Global Health and Foreign Policy



From a broader perspective still, **the notion that meeting the needs of people living with rare diseases is an essential condition for achieving universal health coverage – and, simply, a moral imperative – takes its roots much more deeply into major contributions to 20th century political philosophy.**



For instance, the question of the level of recognition and attention to be granted by a society or healthcare system to rare diseases finds a number of answers in the eminent theory of justice developed by John Rawls<sup>28</sup>, two fundamental principles of which are that:

1. each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all;
2. social and economic inequalities are to be arranged so that they are both: (a) to **the greatest benefit of the least advantaged**, consistent with the just savings principle; and (b) attached to offices and positions open to all under conditions of fair equality of opportunity.<sup>29</sup>

In a 2014 article exploring the implications of Rawls' theory of justice on funding for orphan medicines,<sup>30</sup> Hyry, Roos and Cox also concluded that *"the concept of social justice outlined by Rawls shows that a distinction between the individual and society [...] is bogus"*. Their analysis goes on to dispel the fallacy that a society could not rationally choose to prioritise and fund a life-saving, expensive treatment for a very rare disease, or – more broadly – that the interests of a minority of individual patients should necessarily and by default enter in conflict with the aims of public health and with the best interests of society at large.

<sup>27</sup> "Opening Remarks by H.E. Mr. Sven Jürgenson, Permanent Representative of Estonia at the Rare Disease Day Policy Event, New York, 21 February 2019", accessible here > [un.mfa.ee/opening-remarks-by-he-mr-sven-jurgenson-permanent-representative-of-estonia-at-the-rare-disease-day-policy-event-new-york-21-february-2019/](https://un.mfa.ee/opening-remarks-by-he-mr-sven-jurgenson-permanent-representative-of-estonia-at-the-rare-disease-day-policy-event-new-york-21-february-2019/)

<sup>28</sup> As very well captured in the 2011-2012 ICORD Yukiwariso Declaration, accessible here > [icord.se/wp-content/uploads/2012/08/ICORD-Yukiwariso-Declaration-Final-August-2012.pdf](https://icord.se/wp-content/uploads/2012/08/ICORD-Yukiwariso-Declaration-Final-August-2012.pdf) The theory of justice was originally outlined by John Rawls and can be accessed in the following publications: "A Theory of Justice" (Cambridge: Harvard University Press, 1971) and "Justice as Fairness: A Restatement" (Cambridge: Harvard University Press, 2001).

<sup>29</sup> John Robert Wilson Jr. "Ethics in the service of the rare disease patient: Application of the thought of John Rawls and Paul Ramsey toward the increased availability of orphan drugs" Master's Thesis, Rice University, 1990. Accessible here > [scholarship.rice.edu/bitstream/handle/1911/13482/1342319.PDF?sequence=1&isAllowed=y](https://scholarship.rice.edu/bitstream/handle/1911/13482/1342319.PDF?sequence=1&isAllowed=y)

<sup>30</sup> "Orphan drugs: Expensive yet necessary" Hyry HI, Roos JCP and Cox TM, QJM: An International Journal of Medicine, Volume 108, Issue 4, April 2015, Pages 269–272. Accessible here > [academic.oup.com/qjmed/article/108/4/269/1553261](https://academic.oup.com/qjmed/article/108/4/269/1553261)



The authors also affirm as a corollary and direct consequence of Rawls' thinking that *"those lucky not to suffer from the effects of a rare disease should not use their morally arbitrary good fortune to disadvantage those who do"* and that, in a genuine Rawlsian model, everyone must have an equal right to pursue their life plans, to the extent that ***"the more a disease impairs a person's capacity to pursue their goals, the more urgent it is that their health need is addressed"***.



### The Right Horizon for Universal Health Coverage: Breaking The Burden of Isolation and Restoring Equality for the Most Vulnerable Populations

This emphasis on the equal right of all individuals to pursue their life aspirations regardless of their condition or health status also resonates with the political discourse on social justice put forward in recent decades by Amartya Sen, and particularly with his approach centred around the concept of capability (defined as *"the ability to satisfy certain elementary and crucially important functionings up to certain levels"*<sup>32</sup>). In The Idea of Justice (2009), Sen notes for instance that ***"people with physical or mental disability are not only among the most deprived human beings in the world, they are also, frequently enough, the most neglected"***<sup>33</sup> – a dire reality that advocacy organisations representing people living with rare diseases have long documented all over the world.<sup>34</sup>

A rare disease affects...



<sup>31</sup> [twitter.com/TAvia/status/1112825612064972802](https://twitter.com/TAvia/status/1112825612064972802)

<sup>32</sup> Sen, A. *"Inequality Re-examined"* (Oxford: Clarendon Press, 1992)

<sup>33</sup> Sen, A. *"The Idea of Justice"* (Cambridge, Belknap Press, 2009). See in particular chapter 12 *"Capabilities and resources"*, section *"Disability, resources and capabilities"*, page 258. Also see footnote 32 below.

<sup>34</sup> See for instance *"What is a rare disease?"*, Rare Disease Day. Accessible here > [www.rarediseaseday.org/article/what-is-a-rare-disease](http://www.rarediseaseday.org/article/what-is-a-rare-disease) or *"Juggling care and daily life: The balancing act of the rare disease community – A Rare Barometer survey"*, EURORDIS, May 2017. Accessible here > [download2.eurordis.org.s3.amazonaws.com/rbv/2017\\_05\\_09\\_Social%20survey%20leaflet%20final.pdf](https://download2.eurordis.org.s3.amazonaws.com/rbv/2017_05_09_Social%20survey%20leaflet%20final.pdf)



Elsewhere<sup>35</sup>, Sen remarks how the historical neglect of that dimension in the main schools of thought in the philosophy of justice has in turn tended “to bias practical policies in the direction of inaction, [even contributing] to suppressing the sense of inadequacy that can reasonably accompany the failure to take *a responsible view of the social obligation to the disabled*” – even though “*the tragic consequences of disability can be substantially overcome with determined societal help and imaginative intervention*”.

“

Rare disease patients are a particularly vulnerable group of citizens who experience scarcity of medical knowledge, difficulties in accessing adequate care, as well as isolation from society due to the rarity of their condition and the scattered expertise.



Rüdiger Krech, WHO,  
11 May 2018

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**This last comment is important as it sets a clear path for action** – i.e. that the failure to live up to the social obligation to the most vulnerable populations is no longer acceptable, and that the lack of policy action to address the dramatic consequences of disability is no longer justifiable.

In a 2014 review on the “ethics of the social determinants of health”<sup>37</sup>, Jennifer Prah Ruger further illustrates how health is intrinsically a central value in Sen’s approach, and how health-related capabilities (e.g. the avoidance of premature mortality) are regarded by him not only as ends in themselves from a moral standpoint – but also as instrumental in “enabling” and helping achieve all other ends (e.g. the degree to which individuals have the capability to participate actively in their work, social, and political life, to be well-educated or to be secure in their economic facilities). Ruger also notes that, taken to its fullest extent, Sen’s approach views the expansion of human capabilities (and, by extension, the expansion of the freedom of individuals to choose the life they want to live) as “*the ultimate end of public policy*”. Nowhere is that need more acute than in the most vulnerable categories of the population whose capabilities are constrained to the extreme (as is the case for people living with rare diseases). **Therefore, it is fair to contend that any political strategy designed to apply the ambition of universality to healthcare (as is the case with universal health coverage) must in turn live up to the full implications of its mission and put at its core the needs of the most vulnerable.**

The principles set out in the theories of justice of Rawls and Sen shape a political model characterised by: **an equal right of all individuals to enjoy the full extent of their social freedoms, regardless of the severity of their disability**; a marked commitment and greater sense of urgency in favour of **lending more support to those with the most severe impairment**, rather than addressing first and foremost the most

<sup>35</sup> “Disability and Justice”, Keynote Speech by Amartya Sen at “Disability and Inclusive Development: Sharing, Learning and Building Alliances”, a conference organized by the World Bank, Washington, November 30-December 1, 2004. Accessible here > [bit.ly/2Ey3EOc](http://bit.ly/2Ey3EOc)

<sup>36</sup> [www.youtube.com/watch?v=2LJs0lUly8A&t=4483s](http://www.youtube.com/watch?v=2LJs0lUly8A&t=4483s)

<sup>37</sup> “Ethics of the Social Determinants of Health”, Jennifer Prah Ruger, The Lancet, 18 September 2004. Accessible here > [www.ncbi.nlm.nih.gov/pmc/articles/PMC3988689/pdf/nihms566916.pdf](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3988689/pdf/nihms566916.pdf)



common needs of the multitude; and even, as in the case of Sen, a view that the ultimate horizon of public policy should be to empower **all** individuals to enjoy their capabilities to the fullest.

Far from being unattainable ideals, these principles are being increasingly recognised and recently found one of their best and most compelling translations into actual policy at the highest level globally: the Resolution on Global Health and Foreign Policy adopted by the United Nations' General Assembly on 12 December 2017, one major message of which could be summarised as: **the true benchmark of how inclusive a society can pretend to be is how it addresses the health of its most vulnerable.**<sup>38</sup>



**Figure A** · Official World Health Organization visual for World Health Day 2018, the theme of which was "Universal Health Coverage: Everyone, Everywhere"

<sup>38</sup> Accessible here > [www.un.org/en/ga/search/view\\_doc.asp?symbol=A/RES/72/139](https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/72/139)





### 3. Rare Diseases Must Be A Priority Component of UHC Programmes

#### The False Challenge of Limited Resource Allocation

##### Summary

There is ample research and literature to underline how, even in resource-constrained settings, it is perfectly possible – *and actually perfectly in scope* – to prioritise rare diseases even at the earliest stages of planning for universal health coverage. This ultimately remains a political responsibility, a governance decision and a societal choice rather than a purely economic one, and the implications of this must be fully acknowledged if the transformative potential of universal health coverage is not to be undermined.

A rapid scan of the existing literature reveals a very dense body of articles and reflections written over the years that approach the question of how to implement universal health coverage chiefly under the angle of **setting priorities to distribute and allocate finite resources or health services as “fairly” as possible.**

This line of reasoning raises a new and no less important question: whilst one may agree to the moral or philosophical imperative of including rare diseases as a major pillar of a true universal health coverage system, **is it realistic, feasible or even fair to do so in a context of often extremely constrained resources and inputs?**



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Norheim in 2016<sup>40</sup> agreed for instance that, while the WHO's aspiration to universal health coverage was “*radical*”, in the face of evident resource constraints, “*essential health services [could not] entail all possible services but rather a comprehensive range of key services that are well-aligned with other social goals*”, and thus that priority-setting was unavoidable on the path to universal health coverage. **Do care and/or therapies for rare diseases fit within these “key services”?**

**The answer offered by Norheim is actually positive.** While the author notes that the size of the population affected by a given need tends to be a contested criterion, he nevertheless concludes that all health benefits are ethically relevant and that “*the ethical importance of services for rare [diseases] is captured by the three accepted criteria*”, two of which are “*priority to the worse-off*” and “*financial risk protection*” both

<sup>39</sup> [download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Opening%20Session/1.7\\_Amb%20Hoshino%20Rare%20Disease%20event%20remarks%20%28edit%2019%20Feb%29.pdf](https://download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Opening%20Session/1.7_Amb%20Hoshino%20Rare%20Disease%20event%20remarks%20%28edit%2019%20Feb%29.pdf)

<sup>40</sup> “*Ethical priority setting for universal health coverage: Challenges in deciding upon fair distribution of health services*” Ole F. Norheim, BMC Medicine, 2016 14:75. Accessible here > [bmcmedicine.biomedcentral.com/articles/10.1186/s12916-016-0624-4](https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-016-0624-4)

of particular relevance in light of the abundant literature underscoring **the often drastic loss of social and economic opportunities incurred by people living with rare diseases.**<sup>41</sup>



Persons with rare diseases are often trapped in a vicious cycle of **vulnerability** and **poverty** due to **exclusion** from healthcare and education systems, as well as the job market.



Persons with rare diseases and disabilities are often **marginalised from the job market** not only due to prejudice, stigma and discrimination, but also due to **lack of accessible facilities**, of **flexible working hours** and of adapted roles<sup>42</sup>.



**50% of all rare diseases affect children**, who often face great difficulty to attend school due to **inaccessibility** of facilities and non-adapted teaching methods, but also due to prejudice, stigma and discrimination.



Persons with rare diseases remain a **marginalised and invisible, yet statistically significant population** of nearly 300 million individuals worldwide, suffering from **discrimination** in the areas of health, labour and political inclusion – all prime examples of concrete inequalities that must be addressed in the spirit of SDG 10.

The life-threatening urgency placed on persons with rare diseases to take part in research and clinical trials may also occasionally compromise **their right to the privacy** and due protection of their personal data and health records.<sup>43</sup>



The responsibility of caring for persons with rare diseases **disproportionately falls upon women, and particularly mothers** as rare diseases predominantly affect young children. Their time and efforts to provide unpaid care and domestic work, as well as **the burden it places on their own careers and pursuits** (going as far as forcing them to abandon their employment, with very direct implications on their income, pension and future social payments as well as **their economic independence** overall), is often undervalued and unrecognised.<sup>44</sup>

**Table 3** · A brief overview, across SDGs, of the multifaceted challenges and risks of loss of social and economic opportunities faced by people living with rare diseases. Adapted from « *The "Right to Health" in Rare Diseases: A Practical Contribution to Implementing and Achieving the Sustainable Development Goals* » (NGO Committee for Rare Diseases, Submission to the Office of the UN High Commissioner for Human Rights, February 2018) <sup>45</sup>

<sup>41</sup> See for instance "Why rare diseases are an important medical and social issue" by Schieppati A, Henter JJ, Daina E, Aperia A, The Lancet 2008; 371:2039–41. Accessible here > [www.ncbi.nlm.nih.gov/pubmed/18555915](http://www.ncbi.nlm.nih.gov/pubmed/18555915)

<sup>42</sup> See "La integración laboral y social de colectivos especialmente vulnerables: personas con enfermedades raras, personas con enfermedades mentales y mujeres con discapacidad" [online] By María del Carmen López Aniorte, Profesora Titular de Derecho del Trabajo y de la Seguridad Social at Universidad de Murcia, and Gema Chicano Saura, Profesora Asociada de Derecho del Trabajo. Available at: [www.ilo.org/madrid/fow/trabajo-decente-para-todos/WCMS\\_548585/lang-es/index.htm](http://www.ilo.org/madrid/fow/trabajo-decente-para-todos/WCMS_548585/lang-es/index.htm) [Accessed 8 Feb 2018].

<sup>43</sup> See "Universal Declaration on Bioethics and Human Rights" [online] UNESCO. Available at: [portal.unesco.org/en/ev.php-URL\\_ID=31058&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html) [Accessed 8 Feb. 2018].

<sup>44</sup> See "Juggling care and daily life: The balancing act of the rare disease community" [online] EURORDIS-Rare Diseases Europe. Available at: [www.eurordis.org/news/3000-rare-disease-patients-carers-voice-difficulties-balancing-care-life](http://www.eurordis.org/news/3000-rare-disease-patients-carers-voice-difficulties-balancing-care-life) [Accessed 8 Feb. 2018].

<sup>45</sup> [www.ngocommitteerareddiseases.org/wp-content/uploads/2018/05/NGO-CFRDs-Submission-The-Right-to-Health-in-Rare-Diseases\\_Feb-15-2018.pdf](http://www.ngocommitteerareddiseases.org/wp-content/uploads/2018/05/NGO-CFRDs-Submission-The-Right-to-Health-in-Rare-Diseases_Feb-15-2018.pdf)





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The WHO itself, in its 2014 consultative report Making fair choices on the path to universal health coverage<sup>47</sup>, accepts that “when universal health coverage cannot be realised immediately, making progress fairly and equitably becomes imperative” and also remarks that both fairness and equity “bear on the critical choices on the path to that goal”. In practical terms, when it comes to covering a larger population under a nascent universal health coverage programme or strategy, the WHO recommends to country authorities to first expand coverage “for low-income groups, [...] and other groups disadvantaged in terms of service coverage, health, or both” (all populations which very often intersect with people living with rare diseases, as per footnote 24) and goes as far as noting that “an exclusive focus on cost-effectiveness [concerned solely with the total number of healthy life years] is generally found indefensible [...] there are good reasons to start with those worse off over their lifetime”. **All of these elements are highly compatible with a prioritisation of rare diseases even in the earliest stages of planning for universal health coverage.**

More recently still in 2018, in “Health systems implications of rare genetic conditions in low- and middle-income countries: a case study approach”<sup>48</sup>, Allotey and Reidpath go one step further and contend that “**a resilient and responsive health system providing universal health coverage is one that is able to cope with both the commonplace conditions faced by the majority as well as rare conditions, particularly when experienced by more marginalised groups**”. Building on the experience from a real-life case study – a 4-year old child suffering from Harlequin Ichthyosis in Southeast Asia – the authors shine a new and

<sup>46</sup> [download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Opening%20Session/1.6\\_Amb%20Srivihok%20-%20Rare%20Disease%20Day%20Policy%20Event.NP.JB.pdf](https://download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Opening%20Session/1.6_Amb%20Srivihok%20-%20Rare%20Disease%20Day%20Policy%20Event.NP.JB.pdf)

<sup>47</sup> “Making Fair Choices on the Path to Universal Health Coverage: Final Report of the WHO Consultative Group on Equity and Universal Health Coverage” WHO, 2014. Accessible here > [apps.who.int/iris/bitstream/handle/10665/112671/9789241507158\\_eng.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/112671/9789241507158_eng.pdf?sequence=1)

<sup>48</sup> “Health systems implications of rare genetic conditions in low- and middle-income countries: a case study approach” Allotey PA, Allotey-Reidpath CD and Reidpath DD, Critical Public Health, Volume 28, 2018-Issue 2. Accessible here > [www.tandfonline.com/doi/full/10.1080/09581596.2017.1344772](https://www.tandfonline.com/doi/full/10.1080/09581596.2017.1344772)



different light on rare to ultra-rare diseases, seen not as a threat to the sustainability of a universal health coverage system, but rather as *"an important litmus test of [its] robustness"*.

**To sum up, there is a growing body of literature and evidence to affirm that, even within a finite pool of resources, it is not only possible but actually pertinent and mission-critical to prioritise rare diseases upfront as part of the implementation of a universal health coverage system.**

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**The lack of adequate investment in research and innovation, access to diagnostic, medicines and treatments for the 6,000 conditions that are considered rare is a clear threat to the principle of leaving no one behind.**



Leslie Wade,  
Office of Inter-Governmental Support and  
Coordination for Sustainable Development,  
United Nations Department of Economic and Social  
Affairs (DESA),  
21 February 2019

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<sup>49</sup> [download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Opening%20Session/1.4\\_Leslie%20Wade%20Keynote%20address%20at%20Rare%20Diseases%20Day\\_REV4.pdf](https://download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Opening%20Session/1.4_Leslie%20Wade%20Keynote%20address%20at%20Rare%20Diseases%20Day_REV4.pdf)

## 4. The Time to Integrate Rare Diseases into UHC is Now

A Fundamental Political and Societal Choice, Pioneered Today Across the Globe

### Summary

The choice to push for a greater integration of rare diseases into universal health coverage programmes should not be misunderstood as a purely technical or administrative type of decision – it is first and foremost a political one, that should be grounded in a vision for a more inclusive society. That political choice is not a difficult or impossible one to make, as illustrated by many national examples around the world, in developed and developing regions alike. These pioneering examples must serve as a “guiding light” for today’s and tomorrow’s policymakers and help advance the case that people living with rare diseases worldwide need and deserve to play an active role in the advent of more integrated universal health coverage models that also deliver for them.



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While exploring the same issue as Norheim, Allotey and others, Rumbold, Baker, Ferraz et al. took in 2017 a slightly different route, focusing rather on the perceived frontal opposition between priority-setting in healthcare systems and individuals’ right to health.<sup>51</sup> While they also reach the same conclusion that both notions do actually have a common grounding and can be mutually dependent and mutually reinforcing, they also raise an additional and interesting dimension by noting that, *“when an acceptable interpretation of the content of the right to health under national law has been clarified, [...] finance ministers should reappraise their budgets, considering the state’s obligations under that right. The right to health, just as civil and political rights, requires resources, whether through taxation or other means. As with civil and*

<sup>50</sup> “All roads lead to universal health coverage” Adhanom Ghebreyesus T, 17 July 2017. Accessible here > [www.who.int/news-room/commentaries/detail/all-roads-lead-to-universal-health-coverage](http://www.who.int/news-room/commentaries/detail/all-roads-lead-to-universal-health-coverage)

<sup>51</sup> “Universal health coverage, priority setting, and the human right to health” Rumbold B, Baker R, Ferraz O et al. The Lancet, Volume 390, Issue 10095, P712-714, August 12, 2017. Accessible here > [www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)30931-5/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)30931-5/fulltext)



*political rights, the right to health is supposed to be binding. When the status quo fails to uphold rights, changes, including judicial remedies, are needed."*

This observation underlines an important truth. The decision to implement a universal health coverage system is not, and cannot be reduced to, a purely administrative one that would merely look at the reorganisation or redistribution of a finite pool of resources across many competing targets and objectives. **It is by essence a political responsibility, a governance decision and a societal choice**, which should dare question upfront whether the size of the existing pool of resources is adequate and commensurate to the population needs that must be satisfied.

A few years earlier in 2015, Greer and Méndez had noted exactly this, as they remarked that *"there is a strong tendency to discuss universal health coverage as though it were a settled goal that only requires technical follow-up: this approach contradicts or at least underplays a large body of evidence suggesting that universal health coverage is potentially transformative and intensely political, and depends on the features of a country's governance"*.<sup>52</sup>

Even more recently, the October 2018 Astana Declaration adopted in the wake of the Global Conference on Primary Health Care reaffirmed *"the primary role and responsibility of governments at all levels in promoting and protecting the right of everyone to the enjoyment of the highest attainable standard of health"*, and also that the path towards universal health coverage requires to **"make bold political choices for health across all sectors"**.<sup>53</sup>

Are such "bold political choices" impossible or particularly difficult to make? Nothing could be farther from the truth. Many such examples of successful initiatives to embed the defence of people living with rare diseases in universal health coverage programmes from the earliest stages onwards can actually be found across the globe.

**“As a country that has been supporting persons with rare diseases under our universal health coverage system for more than half a century, we are grateful that the issue of rare diseases is gaining momentum as a key policy area at the United Nations.**



H.E. Toshiya Hoshino,  
Ambassador and Deputy Permanent  
Representative, Permanent Mission  
of  
Japan to the United Nations,  
21 February 2019

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<sup>52</sup> "Universal Health Coverage: A Political Struggle and Governance Challenge" Greer SL and Méndez CA. American Journal of Public Health, 2015;105:S637–S639. Accessible here > [ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2015.302733](http://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2015.302733)

<sup>53</sup> [www.who.int/docs/default-source/primary-health/declaration/gcphc-declaration.pdf](http://www.who.int/docs/default-source/primary-health/declaration/gcphc-declaration.pdf)

<sup>54</sup> [download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Opening%20Session/1.7\\_Amb%20Hoshino%20Rare%20Disease%20event%20remarks%20%28edit%2019%20Feb%29.pdf](https://download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Opening%20Session/1.7_Amb%20Hoshino%20Rare%20Disease%20event%20remarks%20%28edit%2019%20Feb%29.pdf)

**Japan** is widely recognised today as a true champion of, and global leader on, all matters pertaining to universal health coverage, acting most recently as a driving force for the creation within the United Nations system of the “Group of Friends of UHC” which gathers at this moment in time over 40 countries with one common goal.

As a pioneer of universal health coverage domestically, Japan has achieved remarkable positive outcomes over more than 50 years, and first and foremost one of the world's highest levels of life expectancy and health care standards. The Japanese model is firmly grounded in the principles of universal coverage with compulsory public health insurance, of free access to mostly private medical providers, and of high-quality health care services at low costs. It stands today as one of the best illustrations yet in real life of how advanced and performing an operational universal health coverage model can be.

### Case Study

#### Japan's “Nan-Byo” National Strategy

Find out more by  
scanning the QR code  
below:



But it is also telling to note that **Japan has also historically been at the forefront of addressing, within that universal healthcare approach, the needs of persons living with rare diseases for greater recognition and long-term support.** Japan's national “Nan-Byo” strategy centred around “intractable” and rare diseases takes its roots as far back as the 1970s, and has focused over the years on creating off the ground new solutions to improve care for Japanese citizens affected by rare diseases – ranging from the establishment of a vast network of specialised medical institutions to measures to reduce the financial burden on individuals from seeking and receiving the care they need (e.g. through reduced co-payment of medical fees or through channeling fiscal income from increases in consumption tax to support a fair social insurance benefits programme). The creation of a Japan Intractable Diseases Information Centre (JIDIC) also went a long way to augment and widen the information available about rare conditions to the general public but also to public decision-makers and healthcare professionals as well as patients and caregivers.

Initial measures and steps gave way, in 2014-15 to the enactment and implementation of a national “Intractable and Rare Diseases Act” which further consolidated and enshrined into policy the place and recognition of persons living with rare diseases in the Japanese healthcare system.



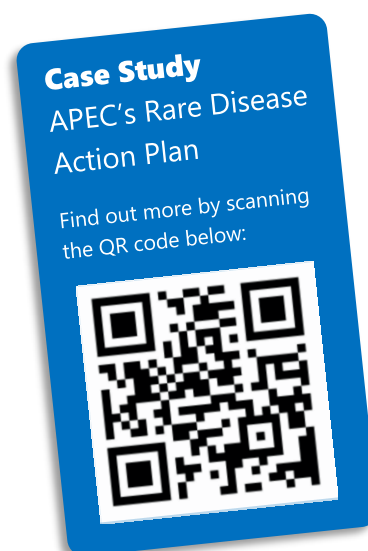
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Besides Japan, **the Asia-Pacific region as a whole** has been making steadfast progress in recent years, as illustrated by **the recent launch of a new Rare Disease Action Plan by the APEC Life Sciences Innovation Forum (LSIF)'s Rare Disease Network** during the APEC CEO Summit 2018 "Harnessing Inclusive Opportunities, Embracing the Digital Future", which gathered the Heads of State of the 21 Pacific Rim member economies, business leaders and innovative thinkers from 15 to 17 November 2018 in Port Moresby, Papua New Guinea. This new Rare Disease Action Plan aimed at providing all APEC Member States with a united framework for policy action to tackle the challenges of rare diseases by 2025, with a focus on 10 key areas including: raising public awareness of rare diseases; better use of technology to enhance the purposeful use of data in clinical decision-making; and healthcare system design to ensure that patients are diagnosed and cared for in a timely manner.

In the **Philippines**, the last 5 years have just seen major policy steps taken towards a stronger recognition of rare diseases – first in 2016 with the adoption of the milestone Rare Diseases Act (Republic Act 10747) and more recently still in 2018-19 with the development of a new Universal Health Coverage Act (pending signature at the time of writing), which will further consolidate specific provisions of the 2016 Rare Diseases Act.

These advances, which were strongly supported and inspired from the outset by civil society (and in particular the Philippine Society for Orphan Disorders), helped enshrine into national policy the rights of persons living with rare diseases, and namely their right to survival and full and healthy development through access to timely health information but also adequate medical care.

The new legislation provides for a comprehensive model of care (e.g. with nationwide newborn screening, the set-up of a national rare disease registry or still the definition of a special benefit package for individuals affected by rare conditions) that will foster greater integration at all stages between relevant institutional stakeholders but that will also have earmarked financing sources and channels to ensure its own sustainability over time (e.g. through either fiscal incentives or new tax/customs exemptions for all activities related to rare disease research, registry maintenance or medicine procurement).



<sup>55</sup> [www.apec.org/rarediseases/News/APEC-Rare-Disease-Action-Plan-Sets-Precedent-to-Integrate-Rare-Disease-Care-by-2025](http://www.apec.org/rarediseases/News/APEC-Rare-Disease-Action-Plan-Sets-Precedent-to-Integrate-Rare-Disease-Care-by-2025)



The latest Universal Health Coverage Act being finalised for enactment in 2019 will go one step further to strengthen the 2016 Rare Diseases Act, affirm once more that no one in the country should be left behind because of any specific health condition, set up new Health Technology Assessment pathways and also expand the sources of funding available to address the needs of specific under-served communities like persons living with rare diseases. **The remarkable example of the Philippines illustrates how, even in a country where progress towards a greater recognition of rare diseases has been much more recent and emerging, a momentum has been found to firmly embed rare diseases in a universal health coverage perspective from the outset.**

### Case Study

Integrating Rare Diseases in the  
Philippines' National Health System

Find out more by scanning the QR code:



This example is just one of many, across all regions of the globe. It bears many similarities for instance with the journey of our community in **Colombia**, where rare diseases have come to greater prominence in the political arena since the beginning of the 2010s with national law 1392. That seminal piece of legislation set in motion a process which saw in the following years the establishment of a more comprehensive list of rare diseases at the national level coupled with a proper country-wide census of affected people; the set-up of an information system and national registry; and most recently the definition and adoption of a national action plan setting up new reference centres but also earmarking new financial resources to support the translation of these policy advances into real change for all people living with rare diseases.<sup>56</sup>

There is also much to be learned from **small island states** all around the world – ranging from Pacific nations like **Fiji**, which has embraced universal health coverage early on and whose healthcare system looks to support the most vulnerable by achieving *“a degree of vertical equity in financing, with the poor receiving a higher share of benefits from government health spending and bearing a lower share of the financing burden than wealthier groups”*<sup>57</sup>, to European ones like **Malta**, which has historically been a resolute friend of the cause of rare diseases – an issue which featured prominently for instance on the programme of the country's Presidency of the EU in 2017.

<sup>56</sup> For a general overview, please see “Colombia: Implementing a National Rare Disease Plan starting with National Registry”, Escobar Morales G, 21 February 2019, accessible here > [download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Session%204%20-%20national%20policies%20and%20strategies/Session%204.1.3%20German%20Escobar%20-%20Colombia.pdf](https://download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Session%204%20-%20national%20policies%20and%20strategies/Session%204.1.3%20German%20Escobar%20-%20Colombia.pdf) The website of the Colombian Federation for Rare Diseases (Federación Colombiana de Enfermedades Raras, FECOER) also offers much insight into the past and current political panorama: [www.fecoer.org/category/panorama-politico/](http://www.fecoer.org/category/panorama-politico/)

<sup>57</sup> “Financing for universal health coverage in small island states: Evidence from the Fiji Islands” Asante AD, Irava W, Limwattananon S et al. BMJ Global Health, 2017;2:e000200. Accessible here > [researchonline.lshtm.ac.uk/3962268/1/bmjgh-2016-000200.PMC5435255.pdf](https://researchonline.lshtm.ac.uk/3962268/1/bmjgh-2016-000200.PMC5435255.pdf)





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However, examples from many developing countries around the world also highlight the challenges remaining ahead. Achieving the promise of universal health coverage and delivering a meaningful integration of rare diseases into universal health coverage programmes requires continuity of action, sustained investment of resources, and a holistic outlook seeking to address all roadblocks or bottlenecks that may otherwise prevent a genuine transformation of healthcare systems. Commitments by governments are a great step forward, but what matters even more is how these commitments are translated into actual action and policy change with the right means and resources, and how they may thus be sustained in the long run, regardless of political instability or electoral cycles.

To summarise, the over-emphasis on limited resources as a Malthusian constraint that would de facto entail the need to operate impossible choices amongst competing health priorities must be seen for what it is – **an illusion and, truth be told, a “governance default”** whereby political decision-makers implicitly or explicitly decline to elevate the level of priority they give to healthcare and to allocate to that particular policy sector the resources that would be needed to properly meet the needs of their population.

All of the above examples demonstrate without doubt that **any country around the world can today take decisive action to support a greater integration of rare diseases in a universal health coverage model or approach**, regardless of where that country stands in terms of relative economic development or national wealth, and even more so regardless of whether or not that country has a longstanding body of laws and policies in support of the community of persons living with rare diseases. It is possible to make great progress at a rapid pace even if starting from very little. And it is also possible to prioritise rare diseases even in a context of limited national public health resources.

<sup>58</sup> [download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Session%204%20-%20national%20policies%20and%20strategies/Session%204%20-%20Daniela%20Bas%20TPs%20-%20Rare%20Diseases.pdf](https://download2.eurordis.org.s3.amazonaws.com/ngocommittee/UN%20Event%20Feb%202019/Session%204%20-%20national%20policies%20and%20strategies/Session%204%20-%20Daniela%20Bas%20TPs%20-%20Rare%20Diseases.pdf)



Once again, these examples confirm and corroborate that **the choice to take action and give rare diseases the place they deserve in the conversation on universal health coverage is an eminently political one** – and one that reflects the type and inclusiveness of society a government wants to put in place. **It is our hope that the few regional and national case studies outlined hereabove shall serve as an inspiration and a “guiding light” for other regional platforms and national governments to follow suit and translate into concrete policy and legislative measures the high expectations and needs of the global rare disease community.**

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**Health systems can learn a lot from rare diseases to design systems that are fit for the future and effectively contributing to universal health coverage.**



Rüdiger Krech, WHO,  
11 May 2018

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<sup>59</sup> [www.youtube.com/watch?v=2LJs0IUly8A&t=4483s](https://www.youtube.com/watch?v=2LJs0IUly8A&t=4483s)



## Conclusion

### Rare Diseases and Universal Health Coverage: A Common Journey Ahead

In the 2016 commentary article Universal Health Coverage – The Critical Importance of Global Solidarity and Good Governance<sup>60</sup>, WHO's Andreas A. Reis observed that *"universal health coverage as a major global health goal is not only a political, but also an ethical endeavour [of which] solidarity is an important underlying concept"*. **Leaving rare diseases outside of current and future efforts to implement universal health coverage across the globe, or not giving them the level of priority which they fully deserve within these efforts, would be not just a major oversight, but simply a moral and intellectual betrayal of the principle of solidarity which sustains the very foundations of universal health coverage as a political notion and ambition.**

The words of Helen Clark in 2016, which we quoted earlier on in this paper, now take a new resonance. But no less powerful were the words of WHO Director General Dr Tedros Adhanom Ghebreyesus in celebration of Rare Disease Day in February 2018 and February 2019 to reaffirm that **the need to help the more than 300 million persons living with rare diseases worldwide is an essential and non-negotiable component of the spirit and of the letter of the Sustainable Development Goals and, as such, of universal health coverage too:**

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**The vision of the Sustainable Development Goals is a world in which no one is left behind, including people who suffer from rare diseases. Just because a disease affects a small number of people does not make it irrelevant or less important than diseases that affect millions.**



Dr Tedros Adhanom Ghebreyesus, WHO

28 February 2018

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<sup>60</sup> "Universal Health Coverage – The Critical Importance of Global Solidarity and Good Governance: Comment on 'Ethical Perspective: Five Unacceptable Trade-offs on the Path to Universal Health Coverage'" Reis AA in International Journal of Health Policy and Management (IJHPM) 2016, 5(9), 557–559. Accessible here > [www.ijhpm.com/article\\_3216\\_f6b6689263bcd781ec3cfe1e63181bc8.pdf](http://www.ijhpm.com/article_3216_f6b6689263bcd781ec3cfe1e63181bc8.pdf)

<sup>61</sup> [www.who.int/mediacentre/news/statements/2018/rare-disease-day/en/](http://www.who.int/mediacentre/news/statements/2018/rare-disease-day/en/)

In the context of the major milestones coming up in 2019 – namely: the April 29 UHC Multi-Stakeholder Hearing and the High-Level Political Forum to take place both from July 9 to 18 at the ECOSOC level and then from September 24 to 25 at the General Assembly level – **the global rare diseases movement is impatient to demonstrate our readiness to “move together to build a healthier world”, and one in which the more than 300 million people living with a rare disease worldwide will feel at long last better recognised and fully supported.**

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**We now need to make sure that, as we move towards the universal health coverage goals, and as we move towards the General Assembly’s High-Level Political Meeting in September, rare diseases are finding at last their deserved place in these conversations and in the commitments that each Head of State will make.**



Nata Menabde, WHO,  
21 February 2019

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We look forward to having the global rare disease community better represented for the first time at these important debates, and in that process we also look forward to the possibility of submitting our first contributions towards effective solutions that address the need of our 300 million fellow citizens throughout the world, based on the overall orientations laid out in this paper.

**A formal recognition of the needs and expectations of persons living with rare diseases within the Political Declaration due to come out of the High-Level Meeting on Universal Health Coverage in September 2019** would be not only a welcome and long overdue recognition of our community, but also an immense hope as well as a unique encouragement for us to continue taking an active role in this important conversation for years to come.



We hereby call on all partners – UN agencies, national governments, other non-governmental organisations and others – to join us in constructive exchanges to explore and advance our current proposals and, where possible, to ideate new ones together.  
**This common journey must begin now.**

<sup>62</sup> [webtv.un.org/search/rare-disease-day-policy-event-keynote-addresses-session-2-session-3/6005938457001/?term=rare%20diseases&sort=date](http://webtv.un.org/search/rare-disease-day-policy-event-keynote-addresses-session-2-session-3/6005938457001/?term=rare%20diseases&sort=date)

This position paper was developed in consultation with RDI member organisations:



This paper is endorsed by:



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