



UN Resolution on addressing the challenges of persons living with a rare diseases

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[EURORDIS.ORG](https://eurordis.org)



Resolution4Rare campaign & Key Asks

Civil society partners

Common vision: Advocating to elevate the issue of rare diseases as a global public policy priority within the United Nations



Global alliance of organisations of persons living with a rare disease



Legitimate platform to interact with the UN System



European alliance of organisations of persons living with a rare disease holding special consultative status with ECOSOC (UN)

+ Member organisations

Why a UNGA Resolution on PLWRDs?



- A step ahead towards **global recognition and visibility**
- Set in motion a **wave of policy actions** – a catalyst
- Become a point of reference to substantiate the claims of the rare disease community **at national level**
- Help the **development of national strategies**, as well as the **creation of international collaboration**.
- Contribute to the achievement of the **SDGs** and the **UN ambition to “leave no one behind”**.

A contribution towards the Sustainable Development Goals

- The motto '**to leave no one behind**' at the core of the UN Agenda 2030 Sustainable Development Goals, is fit for purpose for persons living with a rare disease
- The challenges of persons living with a rare disease have to be addressed in order to reach a **significant number of these SDGs:**



Key Asks of the Resolution4Rare campaign

1

HUMAN RIGHTS & INCLUSION



Participation of persons living with a rare disease & their families
in society and respect of their human rights

Key Asks of the Resolution4Rare campaign

2

**APPROPRIATE
CARE**



Support the improvement of health and social outcomes with the appropriate care, and within existing resources

Key Asks of the Resolution4Rare campaign

3



Promotion of national strategies and actions to leave no one behind

Key Asks of the Resolution4Rare campaign

4

INCLUSION IN THE UN SYSTEM



Introduction and recognition of rare diseases
into UN agencies and programmes

Key Asks of the Resolution4Rare campaign

5

**MONITOR
PROGRESS**



Regular reports by the UN Secretariat to monitor the progress on the implementation, including feedback from civil society.

Official launch at RDD Policy Event – 4th March 2021

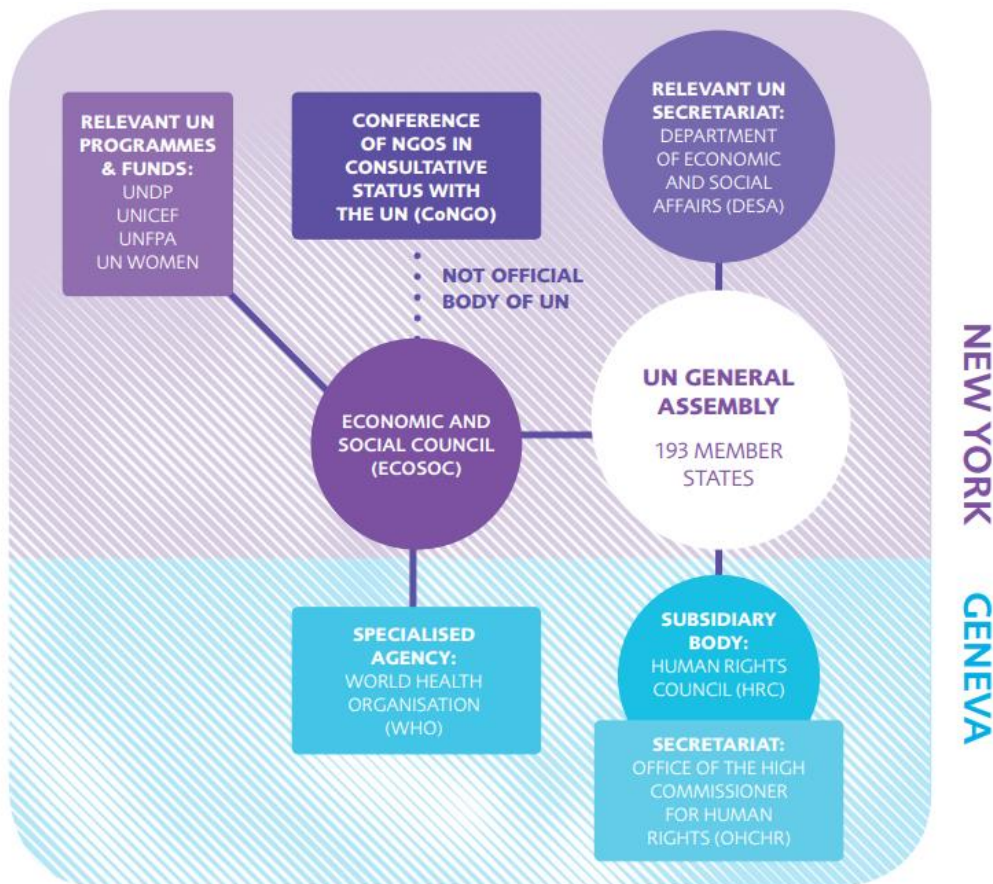


- **Patient testimonies** from NZ, Malta, Kenya, Ghana
- **Champion's message:** Nata Menabde, Director of WHO Office in NYC
- **Support statements from 6 Ambassadors** to the UN: Brazil, Qatar, Spain, France, Japan and Thailand
- Address from **Todd Howland, OHCHR**

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Process towards a UNGA Resolution

The UN System: Why the UNGA?



UN (New York)

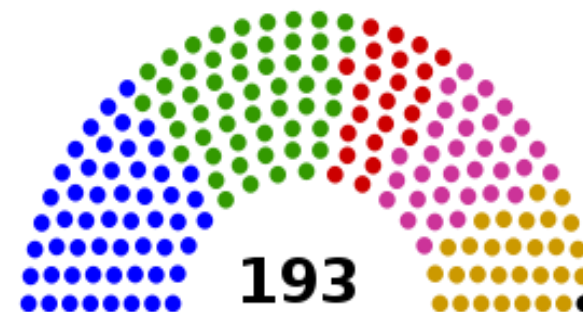
- Agenda 2030 & the Sustainable Development Goals
- Principle « Leave no one behind »
- Universal Health Coverage
- Development agenda: Economic and Social Council (ECOSOC); Department for Economic and Social Affairs (DESA); United Nations Development Program (UNDP)

UN (Geneva)

- Focus only on health: WHO
- Focus only on Human Rights: OHCHR and UN Human Rights Council (HRC)

The UN General Assembly

- The General Assembly assembles **193 Member States**.
- Each Member State of the UN has **one vote** in the GA.
- Often Member States coordinate their votes by **groups** (EU, Small island states...)
- The GA works through a plenary, **Six Main Committees**, a General Committee and a Credentials Committee.
- The GA is **'in session' for the entire year** (Sept to Sept). From mid-September to Christmas is the main part of the GA when most work is carried out by the Committees.
- The 3rd Committee is one of the six Main Committees of the GA and it deals with Social, humanitarian and cultural issues. It consists of all Member States. **The resolution on PLWRD will be presented through the 3rd Committee.**



1st COMMITTEE
Disarmament
&
international

2nd COMMITTEE
Economic
&
financial

3rd COMMITTEE
Social,
humanitarian
& cultural

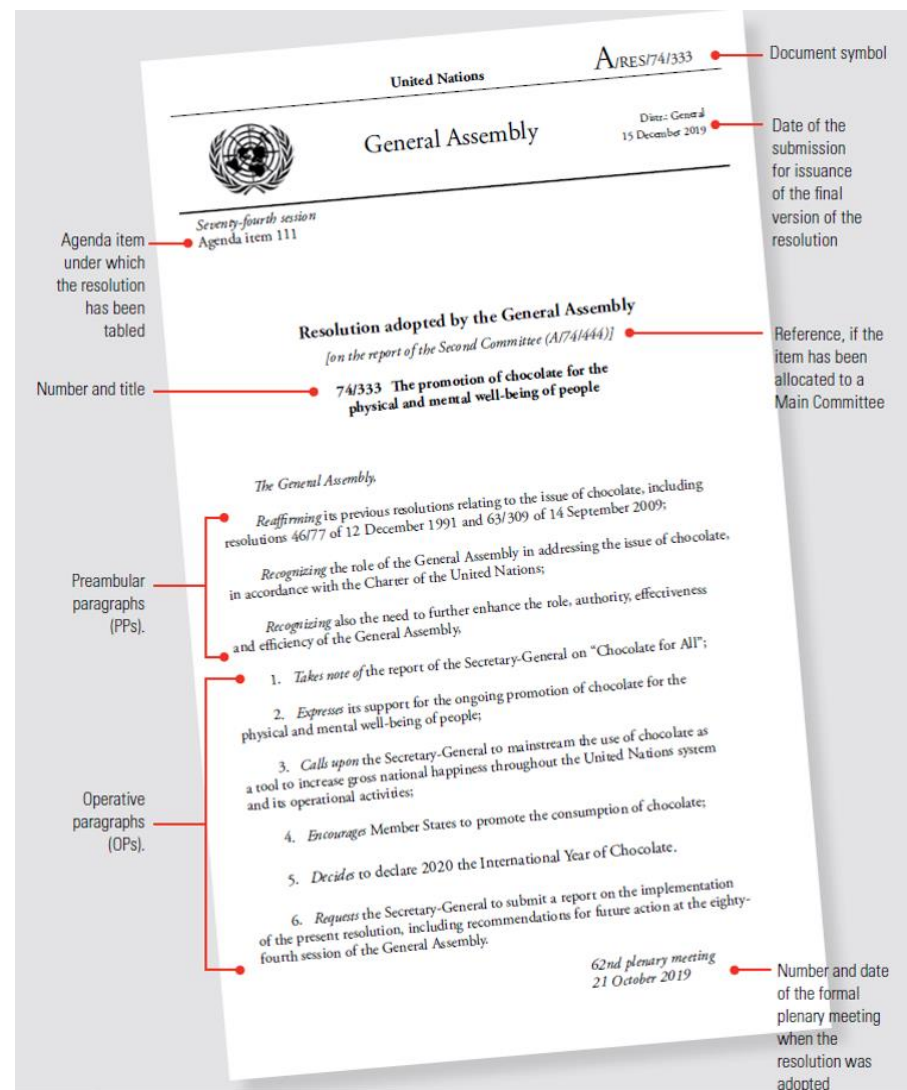
4th COMMITTEE
Special political
&
decolonization

5th COMMITTEE
Administrative
&
budgetary

6th COMMITTEE
Legal

What is a UNGA Resolution?

- A UNGA Resolution represents the view of the 193 Member States
- Reflect the degree of intergovernmental agreement, the evolution of political ideas and the state of global cooperation on a given topic.
- It is **not binding on MS but acts as soft law**, and recalls important conventions and treaties that are binding
- It is **binding on the Secretariat (DESA, OHCHR) and UN Funds & Programmes (UNDP, UNICEF)**
- It is not binding on Specialised Agencies (WHO, World Bank, IMF) – but influences them as the de facto coordinator of UN system



The role of Permanent Missions to the UN

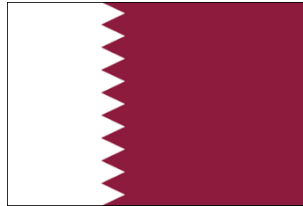


- All Member States have a **UN Permanent Mission** at the UNGA in New York.
- In the Third Committee, **each Member State is represented by one or more diplomats** from the UN Permanent mission.
- Third Committee **meet in October and November to adopt resolutions as drafts and recommend them to the UNGA Plenary.**
- **The Plenary then meets, usually in mid-December,** to consider and adopt recommendations, at which point they **become UNGA resolutions.**

Diplomats liaise back to their Ministry of Foreign Affairs to get approval on whether to adopt the resolution. The MoFA may ask the opinion of the Ministry of Health or the Ministry of Social Affairs.

Getting the support of the Ministries at national level is therefore key in the process, and we need the support of the community!

Core Group of MS supporting the UNGA Resolution on Persons Living with a Rare Disease



Qatar



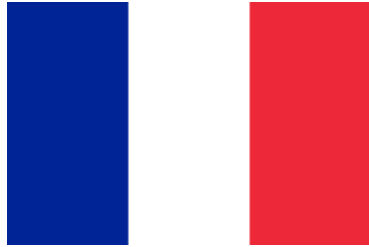
Brazil



Spain

- First working meeting on 9th March 2021
- Will develop 'zero draft' of UNGA Resolution in June
- Will table it under agenda item of the 3rd Committee of the UNGA
- Will lead negotiations on the draft with other UN Member States (July-Oct)
- Will co-organise side-events to gather support from other UN Member States

Other supportive UN Member States



France



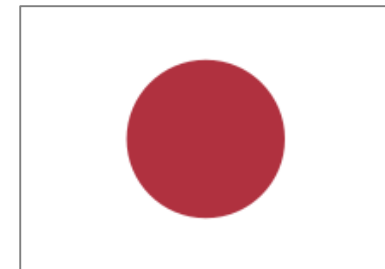
Estonia



Thailand



Kuwait

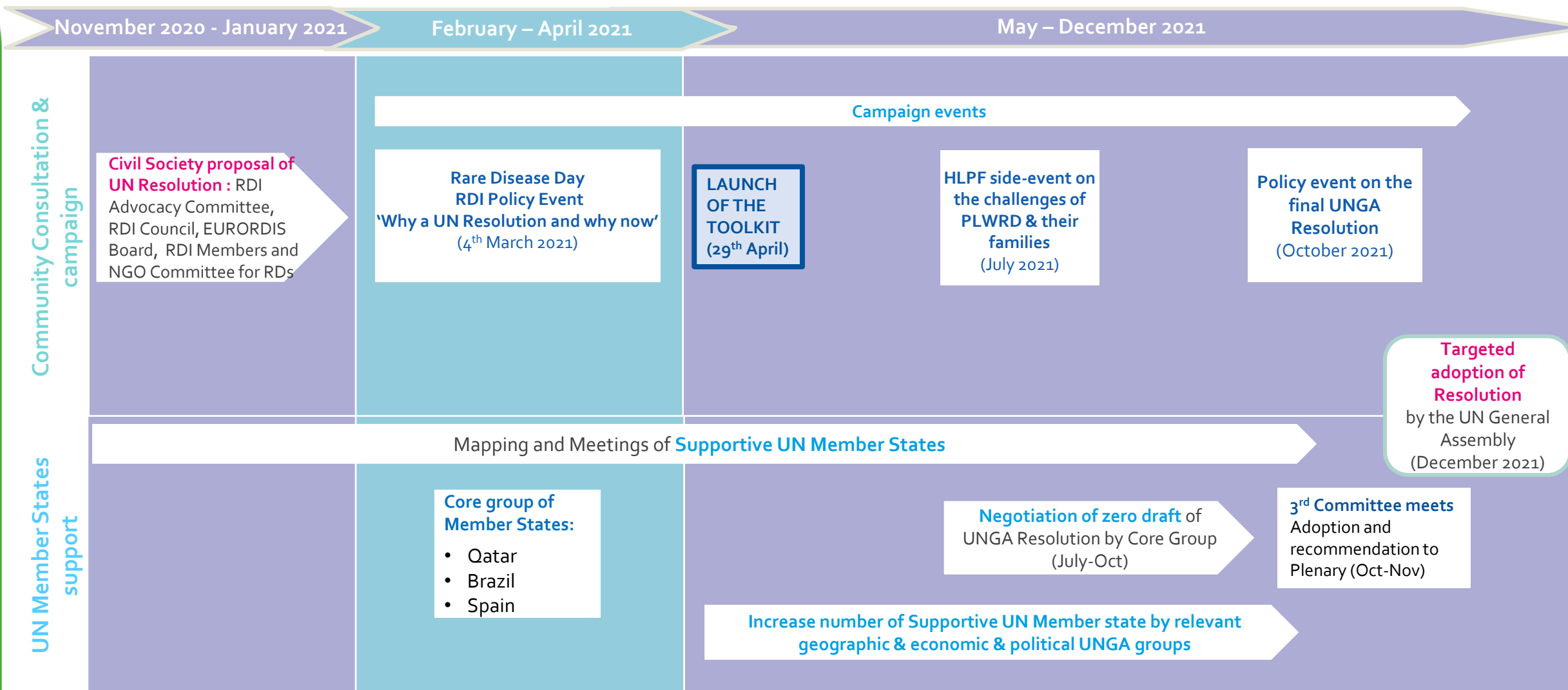


Japan

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**Next steps: How you
can support the call**

Timeline towards adoption



Join the #Resolution4Rare campaign



Toolkit featuring regular and new uploads every month including:

- Letter templates to send to policy makers: Ministry of Health, Social Affairs or Foreign Affairs/Permanent Missions to the UN
- Concept Notes to help you talk about it
- Factsheets
- Posts, images and GIFs to spread the word on social media using the hashtag #Resolution4Rare



Template letter
&
Concept note



Press release



Social media
toolkit

Join the #Resolution4Rare campaign: use the tools!

Facebook, LinkedIn & Twitter



#Resolution4Rare



Key Asks – What is the rare disease community asking for:



Monitor Progress



Human Rights & Inclusion



Inclusion in the UN System



National Action



Appropriate Care

Infographics & Factsheets



Upcoming: a call for testimonies/patient stories to make your voice heard at the UN

Thank you!



Questions?



Email me to set up a one to one call or for
any further information:

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More information on Resolution4Rare:

www.rarediseasesinternational.org/resolution4rare