



UN Resolution on addressing the challenges of persons living with a rare disease and their families

-

What it means? What is next?



RARE
DISEASES
INTERNATIONAL

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UN Resolution campaign on addressing the challenges of Persons Living with a Rare Disease and their families

The official process is underway!



A draft proposal at the Third Committee of the UNGA (Social, humanitarian and cultural issues)

United Nations

A/C.3/76/L.20



General Assembly

Distr.: Limited
11 October 2021

Original: English

Seventy-sixth session
Third Committee
Agenda item 28
Social development

**Brazil, Central African Republic, Equatorial Guinea, France, Italy, Portugal,
Qatar and Spain: draft resolution**

**Addressing the challenges of persons living with a rare disease and
their families**



RARE
DISEASES
INTERNATIONAL

Who is leading the process?

Civil society:



- Social media identity
 - Grassroots campaign with members
- Support to the Core Group of Member States

Core Group of Member States:



Brazil



Qatar



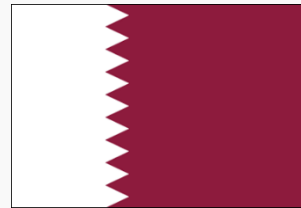
Spain

- Introduction of draft proposal officially
- Organisation of Member States negotiations
- Co-sponsorship of awareness-raising events

Early co-sponsors



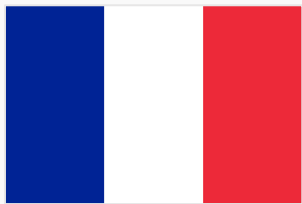
Brazil



Qatar



Spain



France



Italy



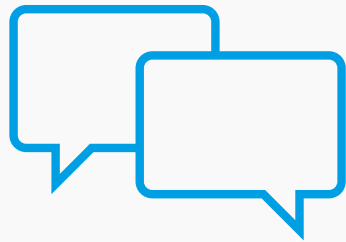
Central African
Republic



Equatorial
Guinea



Who else is joining?



50+ Member States reached by
RDI, EURORDIS and members



84 Member States attended the
1st Consultation

How we got here?



Oct 2016

First High-Level Event
NGO Committee for RDs
United Nations (NYC)



Feb 2019

Second High-Level Event
NGO Committee for RDs
United Nations (NYC)



Jan 2021

Release 5 Key Asks
&
Civil Society Draft Proposal

How we got here?



March 2021

Third High-Level Event
NGO Committee for RDs
(online)



July 2021

High-Level Political Forum
Side-event co-sponsored
by Qatar, Spain & Brazil



Sept 2021

6 Regional Group
meetings

Final steps towards adoption



October: Informal negotiations on the text



November 8: 'Silent procedure' on the final draft



November 15: Discussion and final decision on draft proposal by Third Committee

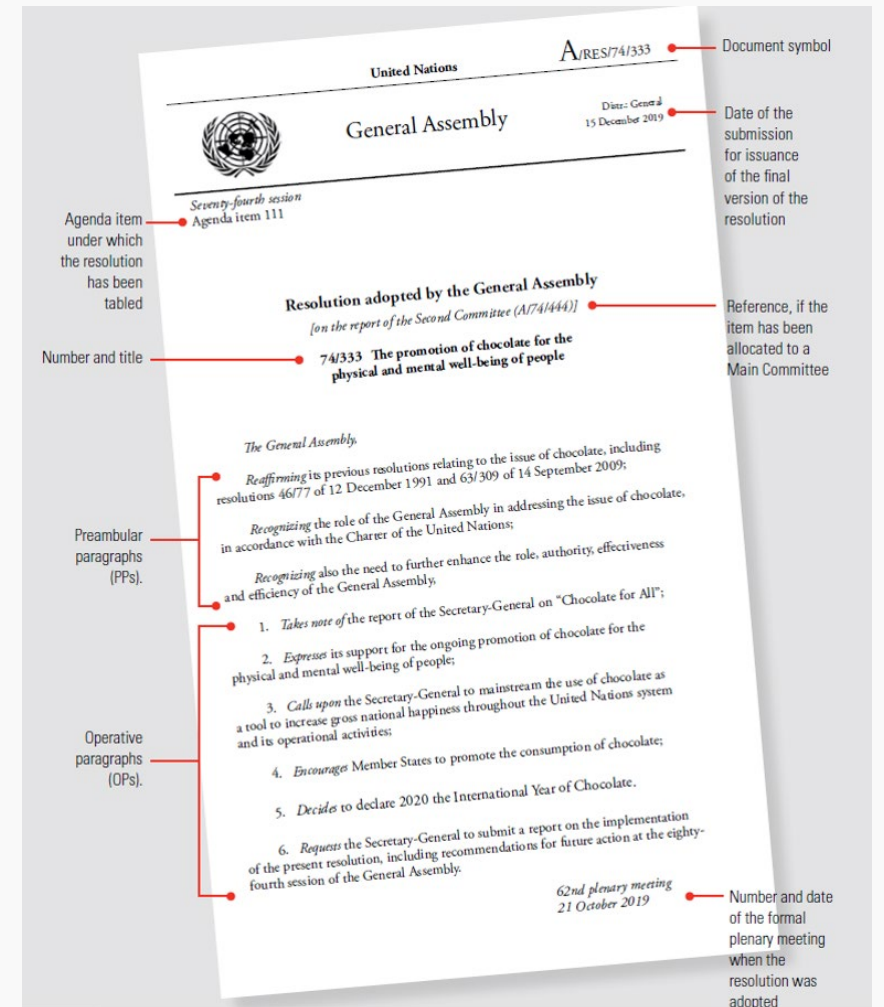


December: Submitted to adoption by UN General Assembly



Reminder: What is a UNGA Resolution?

- A UNGA Resolution **represents the view of the 193 Member States**
- Reflect the **degree of intergovernmental agreement** 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



5 KEY ASKS

HUMAN
RIGHTS &
INCLUSION



APPROPRIATE
CARE



NATIONAL
ACTION



INCLUSION
IN THE
UN SYSTEM



MONITOR
PROGRESS



Opportunities in implementation



Mobilise human rights bodies at national, regional and international level



Work with the Office of the High Commissioner for Human Rights (OHCHR)



Advocate for a Human Right Council Resolution?

Human Rights Council Resolutions

- HRC is a body to ‘address situations of violations of human rights, and make recommendations thereon’
- The Council was created as a subsidiary organ of the UNGA
- Tools to promote human rights (e.g. commissioning OHCHR reports, convening panel debates in the Council)
- Always 3 sessions per year: March (four weeks), June (three weeks) and September (three weeks).
- **A HRC Resolution on PLWRD and their families?**

A suggestion by: Indonesia, Czech Republic, Denmark and Switzerland



Opportunities in implementation



Collaborative clinical networks (ERNs, WHO Global Collaborative Network)



Continue to engage with WHO



A World Health Assembly Resolution?

World Health Assembly Resolutions

- The World Health Assembly is the decision-making body of WHO
- Senior health officials from Member States come to Geneva to participate in the WHA, which takes place every year around May
- Resolutions are not binding, but express the will of member states, representing the highest level of commitment.



Opportunities in implementation



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

Opportunities in implementation



Work with UNICEF



Work with UN Women



*Empowered lives.
Resilient nations.*

Work with UNDP

Opportunities in implementation



Participate in the SDGs volunteer national review (VNR)



Collaborate with national authorities to provide input to the UN report



Continue to gather robust evidence (RareBarometer, National surveys)

Back at the UNGA in 2023?

Current draft proposal of the UNGA Resolution says:

*Requests the Secretary-General, in close collaboration with the Director General of the World Health Organization, to present a **report** to address, inter alia, the challenges faced by persons living with a rare disease and their families, to be submitted during the seventy-eighth session of the General Assembly;*

Decides, considering the multifaceted nature of the challenges faced by persons living with a rare disease, to consider the issue of persons living with a rare disease at its seventy-eighth session, under the item entitled “Social development”.

***The 78th session of the UN General Assembly (UNGA 78)
will open on Tuesday, 12 September 2023.***



Any questions?



THANK YOU!

