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#ACT4RARE

A toolkit for implementing the UN Resolution on "Addressing the challenges of persons living with a rare disease and their families"

RARE DISEASES INTERNATIONAL

UN RESOLUTION
PERSONS LIVING WITH A RARE DISEASE

#ACT4RARE

THE UN RESOLUTION ON "PERSONS LIVING WITH A RARE DISEASE AND THEIR FAMILIES" WAS ADOPTED ON 16 DECEMBER 2022.

NOW WHAT? HOW CAN WE USE IT TO CALL FOR ACTION?

The #ACT4RARE Toolkit provides tools and resources to help you call for action on the commitments made by countries in the UN Resolution.

This is an interactive PDF file. You can click on links, watch videos, and download, print and share resources with your community.

IT'S TIME TO #ACT4RARE !

RARE DISEASES INTERNATIONAL

UN RESOLUTION PERSONS LIVING WITH A RARE DISEASE

#ACT4RARE KIT OBJECTIVES

Let everyone know the UN Resolution on Persons Living with a Rare Disease (PLWRD) has been adopted!

Call for action on the commitments made in the UN Resolution!

Join the global community addressing the challenges of PLWRD and their families!

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ABOUT RDI & THE UN RESOLUTION

Rare Diseases International (RDI) is the global alliance of Persons Living with a Rare Disease (PLWRD) and their families across all countries and all rare diseases.

RDI Members are patient-driven organisations, active in over 150 countries worldwide and address the challenges of PLWRD.

LEARN MORE ABOUT LIFE WITH A RARE DISEASE

Throughout a lifetime, PLWRD and their families face multiple and varied challenges, including when accessing diagnosis, care and services, and experience multiple forms of discrimination.

On 16 December 2021, the United Nations (UN) adopted the first-ever UN Resolution on "Addressing the challenges of persons living with a rare disease and their families."

This milestone is the outcome of consistent and robust advocacy from rare disease civil society groups, PLWRD and families around the world.

LEARN MORE ABOUT THE UN RESOLUTION

The groundbreaking Resolution was adopted by all 193 UN Member States. It is the first UN document to recognise PLWRD and call on the UN, and its Member States, to #ACT4RARE.

ABOUT PLWRD & RARE DISEASES

There are **over 300 million** Persons Living with a Rare Disease (PLWRD) worldwide.

Rare diseases affect **3.5% – 5.9%** of the global population.

The **impact** of rare diseases is felt by PLWRD their families, and loved ones.

Over 6 000 rare diseases have been identified.

PLWRD face many **common challenges,** including difficulty obtaining a diagnosis and care, as well as social barriers to education, employment and participation

THE OPERATIVE PARAGRAPHS

The OPERATIVE PARAGRAPHS of the Resolution state what actions countries have agreed to take to address the challenges faced by Persons Living with a Rare Disease (PLWRD) and their families.

1. Strengthen PRIMARY HEALTHCARE in order to provide quality, accessible, available and affordable, timely, and clinically integrated healthcare services.

2. Adopt GENDER-SENSITIVE national strategies, action plans and legislation to benefit PLWRD and their families.

3. ADDRESS DISCRIMINATION against PLWRD through awareness-raising, dissemination of accurate information on rare diseases and other measures.

4. Emphasize the role of CULTURAL, FAMILY, ETHICAL and RELIGIOUS factors in the treatment, care and support of PLWRD.

5. Collect, analyse and disseminate DATA on PLWRD, disaggregated by income, sex, age, race, ethnicity, migration status, disability, geographical location and other characteristics.

6. Foster the creation of NETWORKS OF EXPERTS, multidisciplinary specialized expert hubs, and the sharing of data, while respecting its protection and privacy.

7. Implement NATIONAL MEASURES which address the disproportionate effect of poverty, discrimination and lack of decent work and employment.

MORE OPERATIVE PARAGRAPHS...

8. Ensure the implementation of the 2030 AGENDA FOR SUSTAINABLE DEVELOPMENT is inclusive and accessible to Persons Living with a Rare Disease (PLWRD).

9. Ensure full and equal access to EDUCATION and lifelong learning opportunities for PLWRD on an equal basis with others.

10. Implement effective programmes to promote MENTAL HEALTH and psychosocial support for PLWRD.

11. Accelerate efforts towards the achievement of UNIVERSAL HEALTH COVERAGE by 2030 to ensure healthy lives and promote well-being for all persons, including PLWRD:

(a) Cover all PLWRD with quality essential health products, health services and quality, safe, effective, affordable and essential MEDICINES, DIAGNOSTICS, and HEALTH TECHNOLOGIES;

(b) Ensure FINANCIAL RISK PROTECTION and eliminate impoverishment due to health-related expenses by stopping and reversing the trend of out-of-pocket health expenditure.

12. Promote access to full and productive EMPLOYMENT and decent work, along with appropriate measures for financial inclusion for PLWRD and their families.

13. Eliminate barriers faced by PLWRD and their families in accessing water, SANITATION and hygiene.

12. Consider the issue of PLWRD at the 78TH SESSION of the United Nations in 2023, under the item entitled "Social development".

WHAT IS POLICY & HOW TO SHAPE POLICY

A policy is a guide for decision-making and a commitment to take specific actions.

In this guide, we speak about implementing, in the regional and national environments, a piece of international public policy - the UN Resolution on "Addressing the challenges of persons living with a rare disease and their families".

Keep in mind that there are other international public policy documents that are important for the global rare disease community, such as the "Political Declaration of the high-level meeting on universal health coverage" (2019).

In this Declaration, UN Member States agree to "Strengthen efforts to address... rare diseases and neglected tropical diseases, as part of universal health coverage".

HOW POLICY IS MADE & IMPLEMENTED

POLICY-MAKING & IMPLEMENTATION OFTEN INCLUDE THE FOLLOWING STEPS, ALL THE STEPS PRESENT ADVOCACY OPPORTUNITIES. THESE STEPS ARE DIFFERENT IN EVERY COUNTRY.

SET AGENDA

Ideas for new policies are introduced on the agenda of decision-making platforms. Strong advocacy can encourage policymakers at all levels to put issues on the agenda.

DESIGN POLICY

Policy proposals are explored and a design is defined.. At this point different stakeholders may be consulted.

DECISION-MAKING

Negotiation, compromise and agreement among decision-makers may lead to the adoption of new policies.

ACTION

Implementation! This is where the commitments made in the UN Resolution can be put into action with specific policies and actions for PLWRD in your country or region.

MONITOR & EVALUATE

Review of policy implementation. Changes made if necessary.

STAKEHOLDER OVERVIEW

FIND PEOPLE, GROUPS & ORGANIZATIONS TO HELP PUT THE UN RESOLUTION INTO ACTION!

RARE DISEASE GROUPS, PLWRD, FAMILIES, FRIENDS, CARERS

PRIVATE SECTOR & BUSINESS

HEALTHCARE CENTRES, RESEARCH INSTITUTIONS & LEARNED SOCIETIES

GOVERNMENT & POLICYMAKERS

MINISTRIES & DEPARTMENTS OF HEALTH, SOCIAL SERVICES, FOREIGN AFFAIRS, ETC.

MEDIA

LOCAL AND NATIONAL PRESS, INDUSTRY PUBLICATIONS, SOCIAL MEDIA NETWORKS & CELEBRITIES

NON-GOVERNMENTAL ORGANIZATIONS

GROUPS FOR HEALTH, VULNERABLE POPULATIONS, HUMAN RIGHTS, EDUCATION, ETC.

SCHOOL ADMINISTRATORS, TEACHERS & LEARNERS

Reach out to policymakers at all levels, from your neighbourhood representative and mayor, to Members of Parliament, ministers and international representatives!

STAKEHOLDER GRID

YOUR COMMUNITY / POTENTIAL CAMPAIGNERS	DIRECTLY INFLUENCE POLICY	INDIRECTLY INFLUENCE POLICY
DIRECTLY IMPACTED Rare disease groups, Persons Living with a Rare Disease & their Families, friends & social networks of PLWRD, carers, etc.	**CAN PROPOSE, DEVELOP & SHAPE POLICY:** • **LOCAL**- Mayor, neighbourhood representative, etc. • **NATIONAL** - Ministers, government departments, etc. • **REGIONAL** - African Union, European Union, Asia-Pacific Economic Cooperation, Organization of American States, etc. • **INTERNATIONAL** - UN Representatives, Ambassadors, etc.	**CAN SHAPE PUBLIC OPINION, RAISE THE PROFILE OF YOUR MISSION, AND RAISE AWARENESS:** Media, civil society groups, other social activists, community leaders & celebrities, etc.
Engage, involve, consult and inform this group at every stage of your advocacy.	Build relationships with policymakers, consult them to draft policy proposals, and find out what influences their decision-making.	Involve and engage this group on specific topics and actions. Ensure they add value to your mission. Be sure their values and priorities complement your mission.

TEMPLATE LETTER - FOR POLICYMAKERS

[Insert your logo here]

[Name Of Recipient
Address]

Subject: Implementing the UN General Assembly Resolution on "Addressing the Challenges of persons living with a rare disease and their families" in [Country]

Dear [Name],

In the name of [Name of your Organisation], the [Name of your country] national alliance for persons living with a rare disease, together with its international partners - the NGO Committee for Rare Diseases, Rare Diseases International (RDI) and EURORDIS-Rare Diseases Europe - we would like to, once again, express our deepest gratitude for [Name of your country]'s adoption, on 16 December 2021, alongside 192 other Member States and by consensus, of the UN General Assembly Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their families".

Now is the time for [Name of your country] to implement this ground-breaking Resolution which "Recognizes the need to promote and protect the human rights of all persons, including the estimated 300 million Persons Living with a Rare Disease worldwide".

People Living with a Rare Disease and their families in [Name of your country] face particular challenges which constitute a gap in the full implementation of the UN Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their families". [Here, give the policy-maker 2-3 facts and/or figures which help them well understand what key challenges Persons Living with a Rare Disease and their families face in your particular country. Pick challenges that are outlined in the UN Resolution].

Furthermore, addressing the challenges of Persons Living with a Rare Disease and their families, a distinctive global community with unique barriers to accessing healthcare, employment, education, and leisure, is necessary if Universal Health Coverage (UHC) is to be achieved by 2030, as is promised in the Political Declaration on UHC, a document in which rare diseases are explicitly mentioned (on page 6).

The implementation of this UN Resolution is a step in the direction of "leaving no one behind" – the goal of the 2030 Agenda. We are eager to seize the opportunities that this Resolution's realization presents for the rare disease community, and look forward to exploring future avenues for collaboration with you. **We would be happy to arrange a meeting with yourself or your colleagues, virtually or face-to-face, to discuss this matter in more detail.**

We, as the national alliance of Persons Living with a Rare Disease in [Name of your country], express our gratitude once more and welcome any further action you can take to improve the lives of your constituents living with a rare disease.

Sincerely,

[Signature – President of National Alliance or Federation
Date
Place]

Click to download the modifiable template letter.

It is available in English, Arabic, Mandarin, French, Spanish and Portuguese. But you can also translate it into any other language.

CHECKLIST TO #ACT4RARE

- USE THE SOCIAL MEDIA KIT TO RAISE AWARENESS AND JOIN CALLS FOR POLICYMAKERS TO #ACT4RARE
- JOIN OR SUPPORT RARE DISEASE ORGANISATIONS WORKING TO SHAPE POLICY
- HOLD ONLINE & IN-PERSON EVENTS IN YOUR LANGUAGE TO RAISE PUBLIC AWARENESS OF RARE DISEASES AND THE UN RESOLUTION
- ORGANISE SEMINARS FOR POLICYMAKERS TO HEAR FROM RARE DISEASE EXPERTS
- RESPOND TO POLICY CONSULTATIONS & COMMENT ON DRAFT POLICY DOCUMENTS
- REACH OUT TO POLICYMAKERS - USE THE TEMPLATE LETTER AND SUMMARY OF THE OPERATIVE PARAGRAPHS OF THE UN RESOLUTIONS
- PRODUCE RESEARCH AND PAPERS ON POLICY ISSUES RELATED TO RARE DISEASES AND THE IMPACT OF LIFE WITH A RARE DISEASE
- CELEBRATE RARE DISEASE DAY (LAST DAY IN FEBRUARY - THE RAREST DAY OF THE YEAR)!

SOCIAL MEDIA KIT

DOWNLOAD

SOCIAL MEDIA KIT

#ACT4RARE

Social media is a powerful tool to raise awareness from anywhere in the world.
In this kit, you will find :

1. Suggested texts
2. Visuals (PNG) for Twitter, Facebook and LinkedIn
3. Animated images options (GIFs)
4. Templates and logos to create your own #ACT4RARE posts
5. Banners, email signatures and virtual background to spread the word

GUIDELINES

Wording

- Use PLWRD as an acronym for Persons Living with a Rare Disease

#HASHTAG

- Add The hashtag #ACT4RARE to all your posts
- Optional hashtags to add : #RareDisease / #Resolution4Rare / #LeaveNoOneBehind / #SDGforAll/ #HealthForAll / #Equity etc...

@TAG

- Tag RDI (Twitter: @rarediseasesint/ Facebook : @RareDiseasesInt / LinkedIn: RARE DISEASES INTERNATIONAL)
- Tag any other person/policymaker/organization who could help implement the UN Resolution. For instance: the United Nations (@UN), the Permanent Representation of your country to the UN, UN Women (@UN_Women), UNICEF (@UNICEF), etc...

SOCIAL MEDIA POST

TWITTER MESSAGES

Calling policymakers to #ACT4RARE

POST 1

Time to act on the commitments made in the @UN Resolution #rarediseases!

All 193 UN Member States promised to 🙌 Implement NATIONAL MEASURES to address discrimination faced by PLWRD 🙌 #LeaveNoOneBehind

Use the #ACT4RARE toolkit to call for action!
📢 Download : (Link to add)

POST 2

In the #Resolution4Rare, @UN Member States promised:

🙌 Full and EQUAL ACCESS to EDUCATION for all Persons Living with a Rare Disease (PLWRD)🙌

Time to #ACT4RARE on the commitments made!
📢 Download the Toolkit to call on your policymakers to ACT: (Link to add)

IMPLEMENT NATIONAL MEASURES

1.

ENSURE EQUAL ACCESS TO EDUCATION

9.

SOCIAL MEDIA POST

TWITTER MESSAGES

POST 3

In the @UN Resolution for Persons Living with a Rare Disease, all countries committed to:

🙌 Accelerating efforts towards the achievement of #UHC by 2030🙌 To ensure #HealthForAll, including PLWRD.

Time to take action!
📢 Download Toolkit to #ACT4RARE : (Link to add)

CUSTOMIZE your message

Choose any of the Operative Paragraph points to call on your country to act on a specific commitment made in the UN Resolution. Then, complete the following text by adding the main idea of the focus you chose.

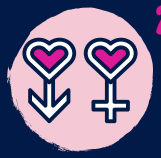
In the #Resolution4Rare, @UN Member States promised:

🙌 (TO BE COMPLETED)🙌 #to add

Time to #ACT4RARE on the commitments made!
📢 Download Toolkit to call on your policymaker to ACT: (Link to add)

BUILD UHC FOR ALL

CHOOSE YOUR MAIN FOCUS



SOCIAL MEDIA POST

FACEBOOK MESSAGES

POST 1

Hashtag options to add :

#Resolution4RARE
#HumanRights
#Agenda2030

Join us to #ACT4RARE 🌎

Time to act on the commitments made in the UN Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families." (PLWRD) @United Nations

Download the ACT4RARE Toolkit to call on your policymakers to keep their promises on:

👉Strengthening PRIMARY HEALTHCARE to provide better quality healthcare services
👉 ADDRESSING DISCRIMINATION against PLWRD through awareness-raising
👉Ensuring full and equal access to EDUCATION for all PLWRD
👉Adopting GENDER-SENSITIVE national strategies, action plans and legislation to benfit PLWRD and their families
👉 Accelerating efforts towards the achievement of UNIVERSAL HEALTH COVERAGE #UHC by 2030 to ensure #HealthForAll, including PLWRD

📢 ACT4RARE Toolkit: (Link to add)

ACT with us today!

SOCIAL MEDIA POST

FACEBOOK MESSAGES

POST 2

It's time to #ACT4RARE 🌎

On 16 December 2021, the global community of PLWRD celebrated the first-ever @United Nations Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families."

Now what? How can the whole #raredisease community use it?

Let's make global policy into local and national action.

📢 Download the #ACT4RARE toolkit to call on your country to take action and implement the commitments made in the Resolution: (Link to add)

Together, we can build ✨ a world where PLWRD and their families experience a better life through full recognition and support ✨

Hashtag options to add :

#SDGforAll
#LeaveNoOneBehind
#Equity
#HealthForAll

SOCIAL MEDIA POST

LINKEDIN MESSAGES

POST :

Join us to #ACT4RARE 🌎

On 16 December 2021, the United Nations adopted the first-ever UN Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families." (PLWRD) @United Nations

Now, it's time to take action on the commitments made in the UN Resolution, including:

▶️ Strengthening PRIMARY #HEALTHCARE to provide quality, accessible, available and affordable, timely, and clinically integrated healthcare services
▶️ Accelerating efforts towards the achievement of UNIVERSAL HEALTH COVERAGE #UHC by 2030 to ensure #HealthForAll, including PLWRD
▶️ ADDRESSING DISCRIMINATION against PLWRD through awareness-raising, dissemination of accurate information on #rarediseases and other measures
▶️ IMPLEMENTING NATIONAL MEASURES to #LeaveNoOneBehind

Download the 🙌 #ACT4RARE Toolkit 🙌 to learn more and call on all countries to ACT 📢 (Link to add)

You can add as many mentions @ as you like to raise the visibility of your post.

For instance, the @United Nations or @ (Any organization/person you think could #ACT4RARE)

SOCIAL MEDIA VISUAL (1/2)

IMAGES

SOCIAL MEDIA VISUAL (2/2)

IMAGES

SOCIAL MEDIA VISUAL (1/2)

DOWNLOAD TO SEE THEM MOVING

GIFS (ANIMATED IMAGES)

SOCIAL MEDIA VISUAL (2/2)

DOWNLOAD TO SEE THEM MOVING

GIFS (ANIMATED IMAGES)

CREATE YOUR OWN : SOCIAL MEDIA VISUAL

Create your own visual with custom templates, graphics, logos and texts

CREATE YOUR OWN : SOCIAL MEDIA VISUAL

Create your own visual with custom templates, graphics, logos and texts

CREATE YOUR OWN : LOGOS

ADD TOLKIT LOGOS TO YOUR VISUALS

RARE DISEASES INTERNATIONAL

RARE DISEASES INTERNATIONAL

NGO COMMITTEE FOR RARE DISEASES

#ACT4RARE

#ACT4RARE

UN RESOLUTION PERSONS LIVING WITH A RARE DISEASE

RESOLUTION ONU PERSONNES ATTEINTES DE MALADIES RARES

RESOLUCIÓN ONU PERSONAS QUE VIVEN CON ENFERMEDADES RARAS

RESOLUÇÃO ONU DESAFIOS DAS PESSOAS VIVENDO COM UMA DOENÇA RARA

BANNERS & BACKGROUNDS

Use the #ACT4RARE visuals for email signatures, social media banners, and virtual backgrounds for online meetings.

SOCIAL MEDIA COVERS

EMAIL SIGNATURE

VIRTUAL BACKGROUND

Don't hesitate to add your own logo to customize your social media cover and virtual background!

You will also find 2 email banners:

- One to promote the webinar
- One to promote the hashtag #ACT4RARE

DOWNLOAD

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PERSONS LIVING WITH A RARE DISEASE