

MEETING REPORT

Fourth High-Level meeting of the NGO Committee for Rare Diseases

28 February 2022 | Expo 2020 Dubai



A GLOBAL
PRIORITY
FOR EQUITY

Celebrating the adoption of the
UN Resolution on "Addressing the
Challenges of Persons Living with a
Rare Disease and their Families" on
RARE DISEASE DAY 2022



NGO COMMITTEE FOR
RARE DISEASES



ÅGRENSKA



RARE
DISEASES
INTERNATIONAL



EURORDIS
RARE DISEASES EUROPE

ORGANIZERS



NGO Committee for Rare Diseases is a substantive committee established under the umbrella of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO). It aims to promote collaboration and actions for PLWRD within the UN.



Rare Diseases International (RDI) is the global alliance of PLWRD and their families. Through its membership of 82 organisations, RDI is active in over 100 countries worldwide.



EURORDIS-Rare Diseases Europe is the alliance of 984 rare disease patient organisations that work together to improve the lives of the 30 million PLWRD in Europe and beyond.



ÅGRENKA

Ågrenska is a national centre of competence, providing programs for children and adults with disabilities, their families and for professionals supporting the family.

UNDER THE PATRONAGE OF

Queen
Silvia
of Sweden



PARTNERS AND SUPPORTERS



Jann Thesleff
Commissioner General at
Swedish Committee for
Participation at Expo 2020

CONTRIBUTIONS BY

UN AGENCIES



World Health Organization



United Nations Office of the High Commissioner for Human Rights



UNESCO
International Bureau of Education

MEMBER STATES



Sweden, Spain also representing Brazil and Qatar as the Core Group of Member States promoting the UNGA Resolution



INDUSTRY REPRESENTATION



International Federation of Pharmaceutical Manufacturers & Associations

CIVIL SOCIETY PARTNERS



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EVENT OVERVIEW



Rare Disease Day has been held since 2008 on the last day of February to raise awareness of rare diseases and their impact on the lives of the over **300 million Persons Living with a Rare Disease (PLWRD) worldwide, and their families.**

The global event in 2022 marked the Fourth High-level Meeting of the NGO Committee for Rare Diseases and focused on opportunities for implementation of **key intergovernmental commitments**: the recently adopted United Nations General Assembly Resolution on “Addressing the Challenges of Persons Living with a Rare Disease and their Families” (UN RES 74/2) and the UN Political Declaration on Universal Health Coverage.

Event goals:

- Discuss the **impact and implementation of the UN Resolution** at global and national levels
- Explore ways to **increase international collaboration and synergies** needed to make rare diseases a policy priority
- **Build a roadmap for the future of rare diseases beyond health**, with a focus on Africa and low- and middle-income countries

The all-day meeting included multi-stakeholder panels exploring ways to **increase international collaboration** and synergies at national, regional and global levels needed to make rare diseases a **policy priority at all levels.**

In particular, it focused on the **African region**, as the continent is increasingly emerging to the issue and fostering a favourable environment for the creation of pan-African networks in the field of rare diseases. Learnings from the panels, however, went beyond Africa and explored the future of rare diseases in low- and middle-income countries around the world.

Holding the fourth high-level meeting and celebrating Rare Disease Day 2022 at the Swedish Pavilion of the World Expo, which is dedicated to ‘co-creation for innovation’ within the Sustainability District, is perfectly aligned with the vision of the NGO Committee and its partners of **moving towards equity, inclusion, and social justice for PLWRD and their families.**

The Agenda Featured Five Sessions:

1. Impact of the UN Resolution at Global Level
2. Implementation and Impact of the UN Resolution at National Level
3. Supporting Rare Diseases as a Global Priority for Equity
4. Rare Diseases in Africa Today
5. Future Opportunities in Africa and Beyond



“We must remember that for 300 million people worldwide and for their families **every day is rare disease day.** And while they are many, they are **much too often alone**, so thank you for sharing your knowledge and experience in order to improve the lives of everyone living with a rare disease.”

– Queen Silvia of Sweden

EVENT SPEAKERS AND ATTENDANCE

The **hybrid event**, held on Monday 28 February 2022, was hosted at the Sweden Pavilion, World Expo 2020, Dubai, United Arab Emirates. The event was also broadcasted virtually for all around the world to participate.

SPEAKER FACULTY

The speaker faculty showed the **breadth of political commitment** to addressing the challenges of living with a rare disease, while the 25 unique national and international patient communities represented in the programme showed the **truly global nature of the movement toward achieving global equity for rare disease**.

3 United Nations agencies represented

UN OHCHR, WHO, UNESCO

2 UN Member States represented

Sweden, Spain also representing Brazil and Qatar as the Core Group of Member States promoting the UN Resolution

1 Ministry represented

Sweden

2 Global umbrella organizations represented

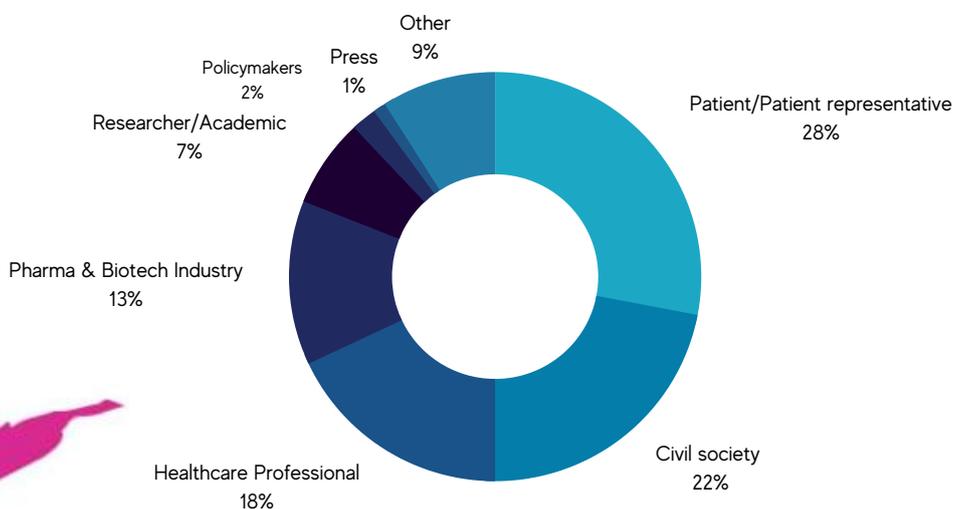
RDI, IFPMA

12 National and International patient communities represented

18 Connections to parallel Rare Disease Day celebrations around the world

ATTENDEE COMPOSITION

The event also served to strengthen existing connections within the rare disease community at large, as well as build **new connections to advocacy communities**, particularly those in the local UAE region.



"I was particularly impressed with the **inspiring messages coming out of the panellists and video testimonies** of people living with rare diseases and their families."
- Rio Hada, OHCHR



EVENT SPEAKERS AND ATTENDANCE

ATTENDANCE NUMBERS



104 Countries represented across 6 continents



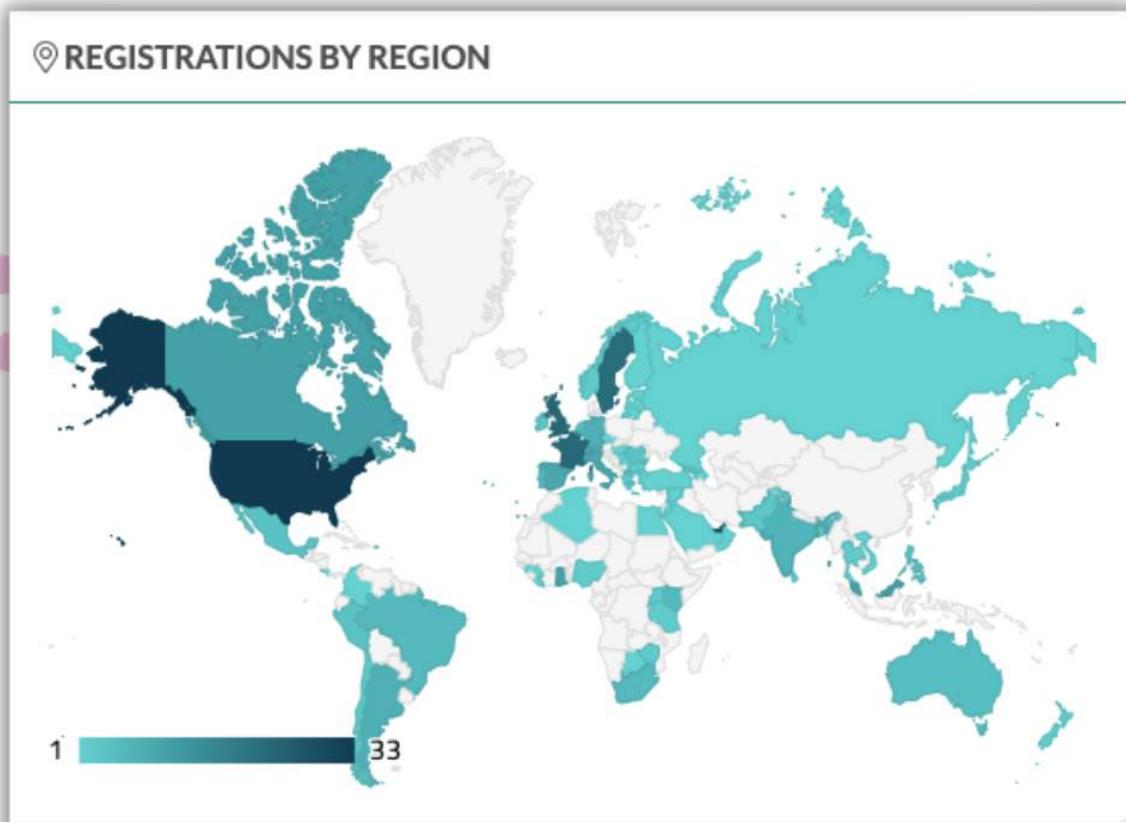
58 In-person participants



1017 Registrations to access the event content



737 Online participants (virtual platform and Facebook Live)



"The event was a great way to meet in person with other rare disease advocates from other parts of the world and just **hear how they are managing their challenges first-hand** in a way you would never experience over Zoom."

- Roselyn Odera, Rare Diseases Kenya



THE UN RESOLUTION AND ITS KEY ASKS



WE



DID



IT

The **Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families,"** promoted by Spain, Brazil, and Qatar and co-sponsored by 54 countries, was adopted by consensus on 16 December 2021, by the 193 Member States of the UN General Assembly.

Presenting the proposal to the UN Third Committee, Maria Bassols, Deputy Permanent Representative of Spain to the UN, affirmed on behalf of the Core Group of Member States that "Persons Living with a Rare Disease are at greater risk of stigmatisation, as well as intersecting forms of discrimination that are obstacles to their full participation in society".

The Resolution recognises the over 300 million Persons Living with a Rare Disease (PLWRD) worldwide, and their families. It **focuses on the importance of non-discrimination and advances key pillars of the Agenda 2030 and its Sustainable Development Goals (SDGs)**, including access to quality education and decent work, reducing poverty, promoting gender equality, supporting innovation, and reducing inequalities.

The **global landmark campaign for equity** that supported the Resolution was the outcome of **coordinated and tireless advocacy** led by civil society partners, including the NGO Committee for Rare Diseases, RDI, and EURORDIS, and **engaged national rare disease groups active in over 100 countries**. The civil society partners worked to illustrate the **needs of PLWRD beyond health and demonstrate the holistic impact of a life with a rare disease on the whole family**.

This first UN Resolution on PLWRD represents a major shift in the global policy landscape, promising greater integration of rare diseases in the agenda and priorities of the UN system.



"We now have **commitment from global community** to address these challenges holistically, and we can **progress toward equity** because equity means doing more for those who have less"
- Flaminia Macchia, RDI



"Reflecting on how much work you've been putting on behind the scenes **makes me hopeful for the future of rare diseases**"
- Youmna Ouraybi, UAE Society for Rare Diseases

THE UN RESOLUTION AND ITS KEY ASKS

HUMAN RIGHTS & INCLUSION



- **Address causes of discrimination** and promote full participation of PLWRD
- Collect and disseminate **disaggregated data** on PLWRD to identify patterns of discrimination

APPROPRIATE CARE



- Strengthen efforts to address the challenges of PLWRD within **Universal Health Coverage**
- Promote **networking of experts and centres** of care globally
- Strengthen **international collaboration and coordination** of research efforts

NATIONAL ACTION



- Encourage UN Member States to adopt / **develop national plans and measures**

INCLUSION IN THE UN SYSTEM



- Encourage Member States, UN Agencies, other relevant international and regional organisations to take action - within the existing resources - to **include PLWRD into the monitoring and evaluation of the SDGs**

MONITOR PROGRESS



- **UN Secretary General:**
 - to present a **Report to the General Assembly on the various social development challenges** faced by PLWRD
 - to consider the **issue of PLWRD as part of their Agenda** under the specific item "**Social Development**"

KEY TAKE AWAYS

The **300 million persons living with a rare disease (PLWRD) worldwide** and their families experience vulnerability and are disproportionately affected by stigma, discrimination, and marginalization in all aspects of their lives. For them, knowledge and information are scarce, and expertise is often not accessible. All of this leads to specific challenges in access to education, healthcare, employment, and leisure, and causes increased impoverishment and isolation. On top of that, the COVID-19 pandemic has worsened all these socio-economic pre-existing inequalities. Therefore, **PLWRD require immediate and urgent attention**, under the auspices of innovative **global, regional, and national policies** that address their needs, respect their human rights, and lead to more inclusive, sustainable societies in line with the **UN Agenda 2030 and the Sustainable Development Goals**.

Stakeholders gathered at the 2022 Global Rare Disease Day event “Rare Diseases: A Global Priority for Equity” and discussed how **key global intergovernmental commitments**, like the United Nations Political Declaration on Universal Health Coverage (UHC) and the recently adopted United Nations General Assembly Resolution on Addressing the Challenges of PLWRD and their families, are **key achievements to raise awareness and visibility, and must trickle down to the regional and national levels**.



Benefits of a
UN Resolution

Achieving global equity
for rare diseases

Focus on Africa and low-
and middle-income
countries

Call for international
support of local efforts



BENEFITS OF A UN RESOLUTION

AT INTERNATIONAL LEVEL

- Immediately **increased visibility** of this invisible population;
- Recognises the **challenges specific to living with a disease that is rare**;
- Sheds light on the **difference between living with a disability** and living with a rare disease;
- Secured stronger **political commitment** at the international level that **opens doors** to other UN bodies, agencies, and programmes and truly address rare diseases holistically;
- Further **connected the international movement** to work together toward a global common goal;
- Established **global legitimacy** to strengthen local action;



AT NATIONAL LEVEL

- **Empowers the rare disease community** as the UN Resolution strengthens the rare disease community everywhere in the world **to drive local change**;
- **Sets groundwork for national advocacy** initiatives thus providing impetus for national patient groups to go to their own policymakers and put rare diseases on the table;
- **Provides guidelines** for what the rare disease community should be advocating for at the local level.



"With a UN Resolution, which affirms there are **more challenges than just health issues**, we are now able to use it as a **toolkit to have dialogue with respective ministers** and other stakeholders. We can go to everyone now and say for this to be a UN Resolution it must be really important, and it **deserves some time from you**"
- Sook Yee and Edmund Lim, SMAcare & WeCareJourney (Malaysia)



"The UN Resolution helps us to **keep rare disease policy a priority for decision-makers**... and acts as a **catalyst for actions and policies** both at the global and national level"
- Nicole Millis, Chief Executive Officer, Rare Voices Australia (Australia)



"I hope that the UN Resolution will help us to get **equity for rare diseases** because we **don't want to be people with disabilities, we want to stay people with rare diseases**"
- Vesna Aleksovska, International Gaucher Alliance (North Macedonia)



"The UN Resolution **brought us more support from physicians and governments**, and we see a bigger commitment to rare diseases now"
- Amira Awada, Instituto Vidas Raras (Brazil)



"The UN Resolution **formalised recognition for the tens of millions of rare disease patients** in our region and around the world"
- Lynn & Majid Jafar, Co-Founders, Loulou Foundation (UAE)



ACHIEVING GLOBAL EQUITY FOR RARE DISEASES

Everyone is entitled to enjoy the highest attainable standards of physical and mental health, and this is closely tied to all other human rights. **The future of rare disease advocacy post-UN Resolution will focus on non-discrimination and advance the key pillars of the UN Sustainable Development Goals (SDGs)**, including access to education and decent work, reducing poverty, tackling gender inequality, and supporting participation in society.

1 NO POVERTY



Reduced impoverishment due to increased expenses related to care

"With visibility and recognition, we can now move toward social justice and equity; equity for a population that accumulates many layers and different levels of vulnerability... Overall this population is at greater risk of impoverishment and social exclusion."

- Flaminia Macchia, Executive Director, Rare Diseases International



3 GOOD HEALTH AND WELL-BEING



Increased medical expertise and public awareness of rare disease

"As we are moving forward on putting the issue of rare diseases on the political agendas of governments, it is now time to follow with actions and health systems strengthening for rare diseases for a global network on rare diseases and for implementing the governance measures against discrimination that we know will work best. The WHO will be moving along this road map together with you."

- Ruediger Krech, Director, Health Promotion Department, World Health Organization



4 QUALITY EDUCATION



Inclusion & Integration in mainstream educational systems

"Quality education is first and foremost an education that prepares for life and for living together in as much harmony as possible, looking after each other, respecting differences and fighting against prejudice and discrimination."

- Amapola Alama, Programme Specialist, UNESCO International Bureau of Education



ACHIEVING GLOBAL EQUITY FOR RARE DISEASES

5 GENDER EQUALITY



Support and gender equality for women as persons with a rare disease and as mothers who often become the primary caregiver

"Women and children in particular deserve our attention. Women living with a rare disease often face multiple discriminations in accessing and retaining decent work. They undertake a disproportionate share of unpaid care and domestic work when some member of their household is living with a rare disease. When they are the ones living with a rare disease, they face greater challenges in accessing sexual and reproductive health care services"

- Agustín Santos Maraver, Permanent Representative of Spain to UN



8 DECENT WORK AND ECONOMIC GROWTH



Support at every step of independent living, from finding, keeping or returning to a decent work and family planning

"I'm happy to learn that the Resolution is stressing the holistic view of what is needed when living with a rare disease. Rather than addressing health problems, which is still the most common approach, Sweden's public health objectives are directed at the societal and cultural level and attempt to put health issues on both the political and social agenda."

- Lena Hallengren, Minister for Health and Social Affairs, Sweden



9 INDUSTRY, INNOVATION AND INFRASTRUCTURE



Increase innovation and diagnostic capacities for rare diseases and ensure equitable access for all

"Our mission is to transform the lives of people affected by rare diseases by continuously innovating and creating meaningful value. It is important and urgent work as across the 7,000 rare diseases, only 5% roughly have an approved treatment and additionally, the diagnostic journey, which is today on average about five years, is far too long."

- Marc Dunoyer, speaking on behalf of International Federation of Pharmaceutical Manufacturers & Associations



10 REDUCED INEQUALITIES



Tackling of aggravated pre-existing inequalities and social exclusion

"As the UN Human Rights Office, our end goal and the message that we bring, is one of equality and non-discrimination, inclusiveness and participation, and dignity and justice. This is where the UN Resolution is significant and ground-breaking, this Resolution emphasises that people with rare diseases have equal rights with others."

- Rio Hada, Officer-in-Charge, Economic, Social and Cultural Rights Section, UN Office of the High Commissioner for Human Rights



FOCUS ON AFRICA AND LOW- AND MIDDLE-INCOME COUNTRIES

KEY CHALLENGES

Advocate leaders from the rare disease community discussed the challenges experienced by PLWRD and their families in Africa and other low- and middle-income countries around the world:

DIAGNOSTICS

- Lack of awareness among health care professionals resulting in multiple visits and challenges in case identification
- Missed or delayed diagnosis resulting in irreversible disease progression
- Slow progression of genetics discipline in Africa; lack of access to diagnostic services or awareness of testing sites, unclear logistics around the process for testing, and limited expertise within the country



CARE

- Lack of access to treatment for those who get an accurate diagnosis
- Limited availability or awareness of local expertise

HEALTH SYSTEM

- Healthcare systems are set up for acute care and not long-term care so when people are being diagnosed with a rare disease the therapies and care is for a short period and not for a lifetime
- Fragmented health systems with hard-to-reach populations
- Limited surveillance and data monitoring; some healthcare systems behave as though rare diseases do not exist

CULTURE

- Stigma by community members assigning guilt to parents of children with rare diseases
- Religious and cultural considerations, including believes in inherited ancestral curses; 60% of Africa's population still go to a traditional healer prior to seeking medicine

POLICIES

- Lack of definition of "rare disease" in many countries
- Competing government priorities, other health problems that might be considered more pressing, such as infectious diseases
- Lack of allocated funding, even where laws exist and difficulty enforcing action plans



FOCUS ON AFRICA AND LOW- AND MIDDLE-INCOME COUNTRIES

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“The identification rates (for hemophilia and rare inherited bleeding disorders) in the region in which North Africa sits is still at around 40% and in Africa over all it is at about 8%. It can be a big challenge: the lab personnel are not trained, the labs are not equipped” – Rana Saifi, World Federation of Hemophilia



“Especially if you have children, or you have a family that has several children with rare diseases, the community starts to look at you in a different way. That adds to the complications you already have to deal with every day” – Roselyn Odero, Rare Diseases Kenya



“One of the pivotal things that we’ve had to do is to work with traditional healers within our continent and have there be a mutual respect for what we are trying to do and what they are trying to do” – Kelly du Plessis, Rare Diseases South Africa

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ROAD MAP FOR THE FUTURE OF RARE DISEASE ADVOCACY

- **Foster local education of community** to reduce stigma and increase awareness of options for diagnosis, treatment and care; recommendations include:
 - Start with your family, your neighbours and your community
 - Speak with a unified voice as a community; reiterate same messages
 - Leverage social media as a powerful tool
 - Ensure you are representing the community and not just your experience when you speak
- **Empower and train individual organization members** to advocate for themselves; strong country leadership is key
- **Ensure strong governance of patient organizations** – e.g., board of directors, medical and scientific advisory committee, succession plans for next generation of leaders – to make organisations more effective, reactive to external drivers and resilient in the face of crisis
- **Work jointly with other stakeholders to achieve holistic support** for PLWRD and their families, including healers, herbalists, pastors
- **Produce data that is meaningful** and can help policymakers make decisions
- **Continue working on public policies and structures** to create sustainable change for PLWRD and their families for generations to come
- **Use UN Resolution as a framework** for local advocacy and when speak with local governing bodies, e.g., African Union.

“



“UN Resolution helps transfer capacity of the different organisations around the world to brings us the right tools to work together with the Ministry of Health” – Roberta Anido de Pena, Argentine Federation of Rare Diseases



“UN Resolution has been a big boost for our efforts... now everyone is saying ‘yes, it is time for us to work on rare diseases together.’” – Carmencita Padilla, Philippines Society for Orphan Disorders

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HOW CAN THE INTERNATIONAL COMMUNITY SUPPORT LOCAL EFFORTS?

Equity of access

Patients in developing countries and lower income countries do not have the same opportunities as others in developed countries, including access to information

Awareness of healthcare literacy

Be cognizant of language used and make materials adaptable to grass roots level efforts

Evidence base development

through strong data collection to show policymaker how health outcomes can be improved and how the quality of life for PLWRD can be changed from a physical and psychosocial point of view

Coordinated advocacy efforts

Speak with one voice as a rare disease community when advocating for change

Evolution of care model

from short-term to long-term healthcare and social service provision; physical therapies and therapies for mental health need to be provided for life

Importance of mental health

Mental health offering should be an integral part of rare disease care and available at the point of diagnosis



“Coming to terms and living with a rare disease is a lot to deal with and there is often no cure and often no treatments at all but **attention to the mental health is rarely given at the point of diagnosis**”
– Lara Bloom, Ehlers-Danlos Society

Capacity building and patient group empowerment

some countries are still young in the rare disease advocacy journey and can learn from others how to best advocate and lead conversations with local governments



“We are young in this rare disease group journey, and it would be **best if we didn't have to reinvent the wheel**; have somebody show us this is what we are supposed to do, because as individuals, we cannot go very far, but **together we'll go very far**”
– Christine Mutena, Rare Diseases Kenya

Benefit of a Regional African Alliance

Advocates see value in a regional alliance in Africa, including:

- Create an environment to **connect and foster enthusiasm** for advocacy
- Build a platform to **network and showcasing advancements** in neighbouring countries
- **Exchange on ideas** for how to adapt advocacy work given local circumstances
- **Share organisational experience** to save others time and investment in figuring out the same challenges others have already gone through
- Decide together on **priorities for the region** and how to achieve these
- Be **part of a community** so no one is alone in the journey



“A Regional Alliance would serve to understand the **road map of where we are now as a continent**, picking up from what has happened in the past and bringing us to the stage where we know the progress we have made.”
– Samuel Agyei Wiafe, Rare Disease Ghana Initiative

WHERE DO WE GO FROM HERE?



Advocacy on the implementation of the UN Resolution on Addressing the Challenges of PLWRD and their families will continue. Civil society partners are now working with the World Health Organization (WHO) to continue the momentum from this historic achievement and call for a resolution that focuses on health equity, strengthening of healthcare systems, and universal health coverage for PLWRD.

Partnerships with other UN agencies and bodies will also be explored to elevate the human rights of PWLRD and the need for a holistic approach to rare diseases.

"The UN Resolution is the **beginning of a whole different saga** in terms of what we can do for rare diseases. What we are innovating and activating in rare diseases has resonance right across all the other diseases. **We are going to be the leaders not just in healthcare but also in all the other sectors** that we are talking about because I think rare diseases are **going to show the world not just how to live with a chronic disease but how to live a quality life to the fullest extent possible.**"

- Durhane Wong-Rieger, Chair of Rare Diseases International Council



Upcoming events:

- RDI Informal Policy Side-event to the World Health Assembly on Strengthening Healthcare Systems – **24 May 2022**
- Rare Disease Day 2023 – **28 February 2023**
- 5th High-Level Policy Event of the NGO Committee for Rare Diseases – **TBD, 2023**





A GLOBAL
PRIORITY
FOR EQUITY

Moderators:



Anders Olauson, Chair of the NGO Committee for Rare Diseases



Durhane Wong-Rieger, Chair of Rare Diseases International Council

FROM GLOBAL FRAMEWORK TO NATIONAL IMPLEMENTATION

IMPACT OF UN RESOLUTION AT THE GLOBAL LEVEL

Welcome remarks

- The Journey of Life with a Rare Disease
- Opening message from Anders Olauson
- Video greeting from Queen Silvia of Sweden
- A message from Queen Letizia of Spain
- A message from Antonio Guterres, UN Secretary General



Anders Olauson, Chair of the NGO Committee for Rare Diseases



Queen Silvia of Sweden

Building the UN Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their Families

- The Making of the UN Resolution: Key figures from the patient community are interviewed about how the community mobilized toward a UN Resolution
- A message from Core Group Member States promoting the UN Resolution (Spain, Brazil, and Qatar)



Agustín Santos Maraver, Permanent Representative of Spain to the United Nations



Tamsin Rose, Senior Health Fellow of the Africa Europe Foundation (interviewer)



Anders Olauson, Chair of the NGO Committee for Rare Diseases.



Durhane Wong-Rieger, Chair of Rare Diseases International Council



Flaminia Macchia, Executive Director of Rare Diseases International



Yann Le Cam, Chief Executive Officer of EURORDIS.



Keynote Speech



Lena Hallengren, Minister for Health and Social Affairs of Sweden

IMPLEMENTATION AND IMPACT OF UN RESOLUTION AT NATIONAL LEVEL

Live greetings from High-Level Conference on Rare Diseases organised by the EU French Presidency at the Ministry for Solidarity and Health



Yann Le Cam, Chief Executive Officer of EURORDIS

Stakeholder roundtable

Moderated discussion with representatives of intergovernmental organizations, medical community, industry, and patient community on the potential impact and opportunities related to the implementation of the UN Resolution.



Rio Hada, Officer-in-Charge, Economic, Social and Cultural Rights Section, Office of the United Nations High Commissioner for Human Rights



Marc Dunoyer, IFPMA - International Federation of Pharmaceutical Manufacturers & Associations (CEO, Alexion and Chief Strategy Officer, AstraZeneca)



Maryam Matar, Founder and Chairperson, UAE Genetic Diseases Association



Flaminia Macchia, Executive Director of Rare Diseases International

Patient Advocate Testimonials

Collection of testimonials from patient advocates representing different regions around the globe discussing what the UN Resolution means to them.



Amira Awada, Vice president, Instituto Vidas Raras



Vesna Aleksovska, Projects officer, International Gaucher Alliance



Lynn & Majid Jafar, Co-Founders, Loulou Foundation



Sook Yee and Edmund Lim, Advocates for Spinal Muscular Atrophy & Rare Conditions, SMAcare & WeCareJourney



Nicole Millis Chief Executive Officer, Rare Voices Australia



BUILDING A ROADMAP FOR FUTURE OF RARE DISEASES

SUPPORTING RARE DISEASES AS A GLOBAL PRIORITY FOR EQUITY

Priority themes from International Organisations

Statements from international organisations about the importance of making rare diseases a priority in achieving global equity.



Rüdiger Krech, Director, Health Promotion Department, World Health Organisation



Amapola Alama, Programme Specialist, UNESCO International Bureau of Education



Michael Lövgren, Development Coordinator, Ågrenska

RARE DISEASES IN AFRICA TODAY

Africa Rare Disease Current Landscape

Moderated exchange of patient experts on African's current rare disease landscape and the recommendations from the First Rare Disease African Summit.

Moderated panel



Rana Saifi, Regional Manager, Eastern Mediterranean, World Federation of Hemophilia



Samuel Agyei Wiafe, Executive Director, Rare Disease Ghana Initiative



Roselyn Kanja Odera, Co-Founder, Rare Disorders Kenya



Christine Mutena, Co-Founder, Rare Disorders Kenya



Kelly du Plessis, CEO, Rare Diseases South Africa

Presentation of key Recommendations from African Summit



Samuel Agyei Wiafe, Executive Director, Rare Disease Ghana Initiative



FUTURE OPPORTUNITIES IN AFRICA AND BEYOND

Africa and Beyond: Where do we go from here?

Moderated exchange on the future of rare disease advocacy post-UN Resolution looking specifically at the topics of healthcare, social care, school, financing, and labour. Followed by live Q&A.



Rana Saifi, Regional Manager, Eastern Mediterranean, World Federation of Hemophilia



Samuel Agyei Wiafe, Executive Director, Rare Disease Ghana Initiative



Roselyn Kanja Odera, Co-Founder, Rare Disorders Kenya



Christine Mutena, Co-Founder, Rare Disorders Kenya



Kelly du Plessis, CEO, Rare Diseases South Africa



Roberta Anido de Pena, President, Federación Argentina de Enfermedades Poco Frecuentes (Argentine Federation of Rare Diseases)



Carmencita Padilla, Chair, Philippines Society for Orphan Disorders



Lara Bloom, President and CEO, Ehlers-Danlos Society

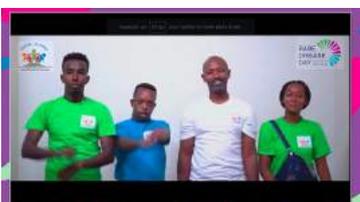


CELEBRATING RARE DISEASE DAY



Special session hosted live on the RDD Facebook page to celebrate with rare disease groups around the world!

442 people watched live
7,6 K have seen the video



ONLINE COMMUNITY



1017

REGISTERED

Access virtual platform and meeting recording



104

COUNTRIES

6

CONTINENTS



SOCIAL MEDIA



#RareExpoDubai

MEETING REPORT

Fourth High-Level meeting of the NGO Committee for Rare Diseases



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