The NGO Committee for Rare Diseases

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NGO COMMITTEE FOR RARE DISEASES

- Substantive Committee under the umbrella of Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)

- **Goal:** promote rare diseases as a priority in global health, research, and social and medical care as part of the UN 2030 Agenda: the Sustainable Development Goals (SDGs).

- **Who is involved?**
  - Initiative by Ågrenska Foundation & EURORDIS - Rare Diseases Europe in cooperation with RDI
  - Supported by 34 NGOs from CoNGO
  - Driven by civil society / Multi-stakeholder
  - Forum for interested parties NGOs, ECOSOC members, UN bodies, individual experts)
OBJECTIVES

* To increase visibility of rare diseases at the global level
* To extend and share knowledge about rare diseases and their unmet needs
* To connect NGOs interested in rare diseases and their partners within a global platform
* To promote international, multi-stakeholder collaboration and actions for rare diseases
* To align rare diseases as a global priority in public health, research and medical and social care policies
* To give input and inform policy within the UN system, at various levels (ECOSOC, WHO, UNESCO, IMF etc.)
What will the Committee do?

- Highlight current or potential opportunities for improved and more integrated collaborations between all stakeholders.
- Create synergies with other CoNGO committees and with NGOs in ECOSOC.
- Encourage all relevant UN bodies to better reflect aspects related to rare diseases into their mission and actions.
- Host dedicated events to share information and to raise the profile of people living with rare diseases worldwide.
- Develop and present reports, recommendations for actions and positions on rare diseases and associated issues.
- Collect and share up-to-date information and research on the global dimensions of rare diseases.
Why get involved in the Committee?

Although the primary purpose of the Committee is to bring together the international community of NGOs, the Committee is inclusive and requires contributions from all stakeholders.

| **NGOs** | • Strengthen your voice as part of a pioneering, global community for rare diseases  
|          | • Initiate dialogue with all rare disease stakeholders  
|          | • Bring your expertise to the discussion  |
| **National Governments** | • Engage with rare diseases experts, especially patients from your country  
|          | • Access up-to-date information about rare diseases collected globally  
|          | • Share experiences of rare diseases strategies to ensure no citizens are left behind  
|          | • Promote your country’s voice, experience and noteworthy initiatives in a global dialogue  |
| **United Nations Representatives** | • Contribute actively to the post-2015 sustainable development agenda in catering to the unmet needs of some of the most vulnerable in society  
|          | • Create partnerships with the most influential rare diseases experts  
|          | • Raise the profile of rare diseases on the global agenda: make the invisible, visible  |
Introducing the Committee: Composition and Members

**Regular Members**
NGOs in consultative status with ECOSOC

**Associate Members**
NGOs in consultative status with other UN bodies than ECOSOC (e.g. WHO, DPI, etc)

**Observer Members**
All other NGOs, governments, patient groups, academic institutions or civil society organisations / Non-profit only

**Supporter Members**
All for-profit undertakings, e.g. private sector organisations

**Individual Members**
Persons actively working for the benefit of people living with rare diseases, or with a noted political or academic expertise on rare diseases

**NGOs in consultative status with other UN bodies than ECOSOC (e.g. WHO, DPI, etc)**
History of the Committee

October 2015

Accepted as a CoNGO Committee

March 2016

By-laws approved by CoNGO president

April 2016

Establishing contacts within UN and member states

November 2016

Inaugural meeting

November 2017

Inception Executive Board is established
The current members of the Inception Executive Board are:

- ÅGRENSKA
- EURORDIS RARE DISEASES EUROPE
- International Alliance of Patients’ Organizations
- International Alliance of Women Alliance Internationale des Femmes
- INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS
- WORLD FEDERATION OF HEMOPHILIA Fédération Mondiale de l’Hémophilie Federación Mundial de Hemofilia
- RARE DISEASES INTERNATIONAL

RARE DISEASES INTERNATIONAL
Formal launch, UN HQ, NY
Rare Disease Day 2019 in New York (exact date tbc)

Aims:

• Bring together members of the NGO Committee for Rare Diseases to discuss achievements, challenges and to plan ahead

• Give visibility to rare diseases by organising an event at the UN HQs in New York

• Attract other NGOs or relevant actors/UN bodies as potential members or partners of the NGO Committee for Rare Diseases
What is required?

- One or various sponsoring national permanent missions to book a room at the United Nations Headquarters in NYC.
- The support of a permanent mission to host/provide a location for a drinks reception for the participants.
- The attendance of representatives of Permanent Missions as speakers or in the audience to raise awareness of our goals and plant the seeds for future collaboration.
NGO Committee strategy:

• Create a favourable environment within the United Nations milieu by organising side-events to UN meetings or producing input such as declarations, papers, comments to United Nations consultations.

• Familiarise all UN Member States that have links to the Committee (through its members: RDI, other NGOs, etc.) to the different activities and explore together the value of a UN Resolution on rare diseases
Intermediate goals:

* Establish good connections with the different agencies and bodies of the United Nations (World Health Organisation, Human Rights Council…)

* Integrate rare diseases into existing agendas and advocacy groupings within the UN like the Non-Communicable Diseases (NCD) alliance or the disability movement.
Intermediate goals:

* Act as contributors: be seen as adding value and innovative ideas to the discussion

* Highlight successes of the RD Community and the possibilities to scale-up to resonate with policy-makers.
How RDI and its members can contribute
RDI & THE NGO COMMITTEE FOR RARE DISEASES

- RDI - is now a member of NGO Committee for RDs

- RDI can **co-produce documents** with NGO Committee i.e. Statements, Contributions, State of the Art of RD activities

- RDI can **co-organise events**, side events, meetings

- RDI can **participate in UN consultations** via members of NGO Committee that have consultative status with ECOSOC and are in official relations with WHO

- Some members of RDI can also be **direct members** of the NGO Committee for RDs
NEXT STEPS TOWARDS THE INTEGRATION OF RDS IN UN POLICIES AND STRATEGIES

Integrate mention of rare diseases in relevant UN Reports, Resolutions (to create precedents)

Create Content:

- Success Stories
- Arguments
- Collect examples of added-value of RDs in various programmes and policies
NEXT STEPS TOWARDS THE INTEGRATION OF RDS IN UN POLICIES AND STRATEGIES

 Advocate to country’s
  - Ministry of Foreign Affairs
  - Ministry of Health
  - Permanent Representations in New York and Geneva

Explore the value of a UN Resolution on Rare Diseases involving the RDI Advocacy Committee