



RARE
DISEASES
INTERNATIONAL

The NGO Committee for Rare Diseases

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Rare Disorders Organization,
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May 10, 2018
RDI 4th Annual Meeting, Vienna

NGO COMMITTEE FOR RARE DISEASES



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)



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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

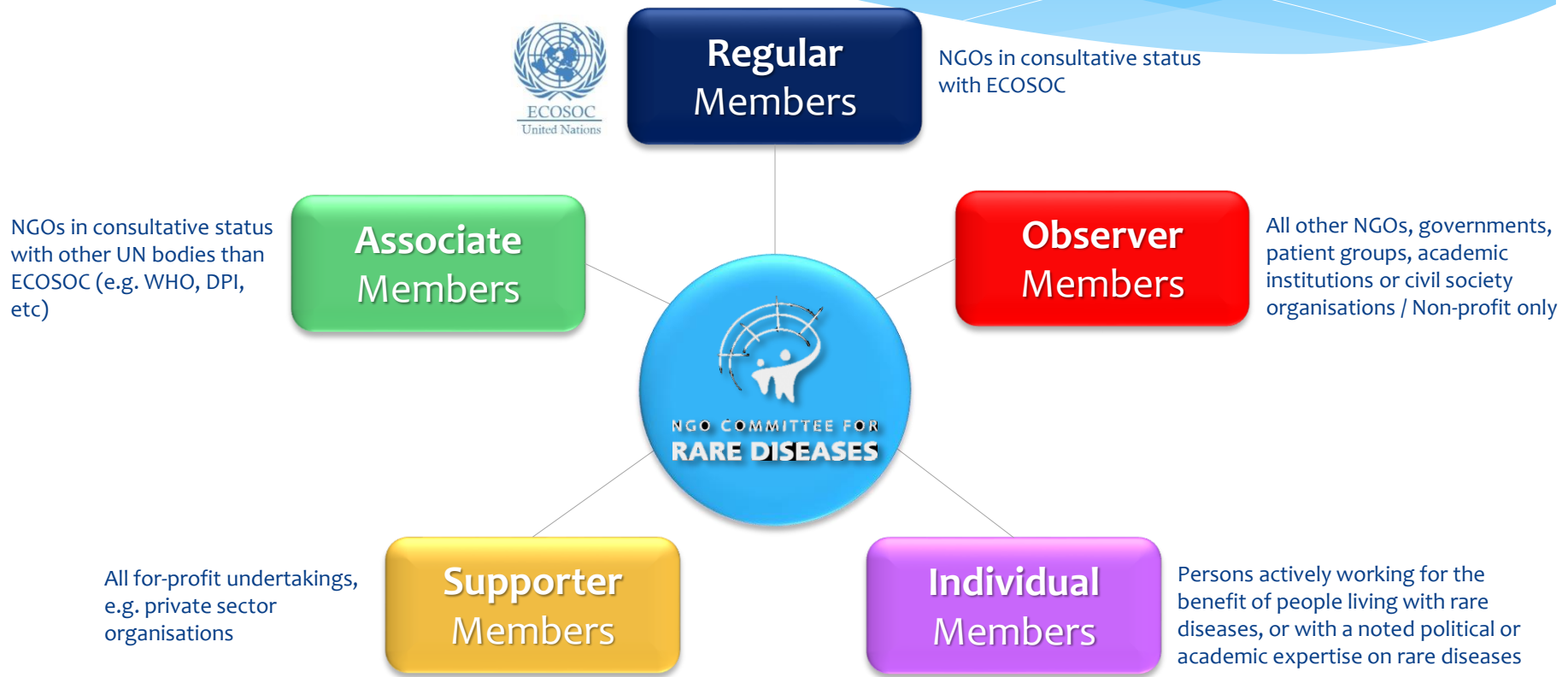
National Governments

- 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



History of the Committee

October
2015



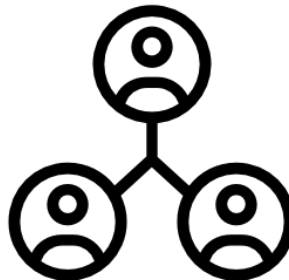
**Accepted
as a CoNGO
Committee**

March
2016



**By-laws
approved by
CoNGO
president**

April
2016



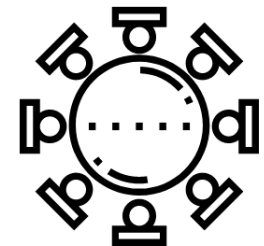
**Establishing
contacts
within UN
and
member
states**

November
2016



**Inaugural
meeting**

November
2017



**Inception
Executive
Board is
established**

INCEPTION EXECUTIVE BOARD

The current members of the Inception Executive Board are:



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11 November 2016

United Nations, New York

The Global Gathering for Rare Diseases

INAUGURATING THE NGO COMMITTEE
FOR RARE DISEASES



Formal launch, UN HQ, NY



Next international event of the Committee

- * 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



Next international event of the Committee

* 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.





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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



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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



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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**



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