



NGO COMMITTEE FOR
RARE DISEASES

NGO Committee for Rare Diseases launches at UN in New York

New York, 11 November 2016 – The NGO Committee for Rare Diseases launches today at the United Nations headquarters in New York.

The NGO Committee for Rare Diseases is a substantive committee established under the umbrella of the Conference of NGOs in Consultative Relationship with United Nations ([CoNGO](#)). **It brings together knowledge and experts to progress towards greater recognition of rare diseases as a global priority in the fields of health policy, research and social and medical care.**

The goal of the NGO Committee on Rare Diseases is to bring visibility and understanding of rare diseases to the United Nations, a platform where they have received little attention until now.

The inauguration event, the ‘Global Gathering for Rare Diseases’, takes place under the patronage of **Queen Silvia of Sweden** and CoNGO, as well as with the support of several national governments.

The launch event brings together over **30 leaders from the international rare disease community** ([see full agenda](#)), including heads of rare disease patient organisations from around the world and international rare disease federations (**Australia, Burkina Faso and Guinea, Canada, China, Denmark, France, Iran, Ireland, Japan, Malaysia, New Zealand, Russia, Sweden, the US and Venezuela**), as well as experts from UN bodies and the European Union.

Anders Olason, Chairman of the Ågrenska Foundation, one of the two founding members of the NGO Committee for Rare Diseases, commented, “Having a rare disease affects all aspects of life; experiences from thousands of families worldwide tell the same story. All areas of life - healthcare, social services, schools, insurances and labour - must work together. Life is holistic, as should care and support be. Working together at the United Nations will make this possible.”

Yann Le Cam, Chief Executive Officer of EURORDIS-Rare Diseases Europe, the other founding member of the Committee, commented, “We are at the start of a new phase of collective action to elevate the cause of people living with a rare disease to become an international public health priority. An international approach will help to ensure that patients and families are gaining attention, support and care in all countries around the world. The NGO Committee will bring these challenges to the forefront of the UN agenda.”

There are over 30 speakers at the event, including:

- Cyril Ritchie, President, Conference of NGOs in Consultative Relationship with United Nations (CoNGO)
- Abbey S. Meyers, Founder & President Emeritus, National Organization for Rare Disorders (USA)
- Navid Hanif, Director, Office for ECOSOC Support & Coordination, UN Department of Economic & Social Affairs (DESA)
- Daniela Bas, Director, Division for Social Policy & Development (DSPD), UN Department of Economic & Social Affairs (DESA)

- Marek Plura, Member of the European Parliament, European Parliament's Committee on Employment and Social Affairs & Vice-President, Disability Intergroup at the European Parliament, via video message
- Durhane Wong-Rieger, President of the Canadian Organization for Rare Disorders and member of the Council of Rare Diseases International
- Dr Christopher P. Austin, Chair, International Rare Disease Research Consortium (IRDiRC), Director, National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health
- John Forman, President, International Conference on Orphan Products & Rare Diseases (ICORD)
- Terkel Andersen, President of EURORDIS-Rare Diseases Europe
- Over 20 senior representatives of rare disease patient organisations from across the world.

About the NGO Committee for Rare Diseases

The NGO Committee for Rare Diseases was initiated by the [Ågrenska Foundation](#) and [EURORDIS-Rare Diseases Europe](#) with the aim to:

- Increase visibility of rare diseases at the global level;
- Extend and share knowledge about rare disease science and policy, and the unmet needs of rare disease patients;
- Connect NGOs interested in rare diseases and their partners within a global platform;
- Promote international, multi-stakeholder collaboration and actions for rare diseases; and
- Align rare diseases as a global priority in public health, research and medical and social care policies.

See more about the Committee's [actions](#) and [objectives](#). Its formation was approved by a vote of 27 CoNGO member organisations in April 2014 and its inception meeting as a substantive committee within CoNGO took place in October 2015. The Committee will aim to ensure that no one person living with a rare disease is left behind and in turn serves to advance efforts to achieve the UN's [Sustainable Development Goals](#) (SDGs).

Helen Clark, Administrator of the United Nations Development Programme, [gave a statement at the recent International Conference on Rare Diseases and Orphan Drugs](#) on the importance of these SDGs as an opportunity to address the specific issues faced by people living with a rare disease. She said, "No country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases."

Organisations interested in becoming a member of the NGO Committee for Rare Diseases please [see here](#).

For more information visit www.ngocommitteerareddiseases.org or follow [@ngorareddiseases](#).

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About rare diseases

The very notion of rarity means that rare disease communities, experts and industry professionals are often few in number and geographically scattered. This means people living with a rare disease are marginalised, as often no one country alone, nor continent, has the critical mass and knowledge needed to address the challenges of living with a rare disease.

The need for collaboration for rare diseases has been recognised and actions are in progress within certain fields. For example in research through [IRDIRC](#), in connecting people globally through [Rare Diseases International](#), [RareConnect](#) and [Rare Disease Day](#) and in industry efforts through [IFPMA's](#) working group for rare diseases.

However, more needs to be done on a global level. There is still an urgent need for a global platform in order to:

- Share the scarce rare disease knowledge that already exists;
- Explore what more could be done or developed to advance knowledge of rare diseases at a global level;
- Connect rare disease stakeholders across borders and diseases;
- Create synergies with other stakeholders to mutually exchange knowledge and expertise; and
- Receive recognition and attention at the UN level, where rare diseases remain an area little explored but with great social and economic impact.

The European Union considers a disease as rare when it affects fewer than 1 in 2,000 citizens. Over 6000 different rare diseases have been identified to date, affecting over 60 million people in Europe and the USA alone.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.