The Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)

With the support of
The Swedish Ministry of Health and Social Affairs

The Permanent Mission of Estonia to the UN

The Government of the Republic of Malta

Under the patronage of
Queen Silvia of Sweden

And

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The NGO Committee for Rare Diseases is a substantive committee established under the umbrella of the Conference of NGOs with Consultative Relationship to the United Nations (CoNGO). The NGO Committee for Rare Diseases was initiated by the Agenda Foundation and EURORDIS-Rare Diseases Europe, with the later integration of Rare Diseases International (RDI), with a view to bringing greater political recognition of the challenges of rare diseases at the global level. 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 in New York.

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www.agrenska.se www.eurordis.org www.rarediseasesinternational.org

Graphic design
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1. **Morning Plenary:**

   • The United Nations and Civil Society: CoNGO and CoNGO Committees
   • Mr Cyril Ritchie, President of CoNGO 2011-2018
   • Mr Anders Olauon, Chairman, Ågrenska
   • Panellists: Mr Cyril Ritchie, President of CoNGO 2011-2018
   • Dr. Ana Rath, International Advocacy, EURORDIS-Rare Diseases Europe
   • Ms Yukiko Nishimura, President and CEO, Canadian Organization for Rare Disorders (CORD); Former Chair, International Rare Disease Research Consortium (IRDiRC)
   • Ms Lauren Barredo, International Advocacy, EURORDIS-Rare Diseases Europe
   • Ms Durhan Wong-Roger, President and CEO, Canadian Organization for Rare Disorders (CORD); Former Chair of the Governing Board, International Alliance of Patients’ Organizations (IAP0)

2. **The Global State of Play of Rare Diseases**

   • Mr Yann Le Cam, Chief Executive, EURORDIS-Rare Diseases Europe
   • Ms Abby S. Meyer, Director, National Center for Advancing Translational Sciences (NCATS); Chair, International Rare Disease Research Consortium (IRDiRC)
   • Ms durhane sarkissian, Former President, International Conference on Rare Diseases and Orphan Drugs (ICRDO)
   • Ms Daniela Bas, Director, Division for Social Policy and Development (DSPD), UN Department of Economic and Social Affairs (DESA)
   • Ms Rachel Yang, Founder, Fondation International Tierno et Mariam
   • Ms Irina V. Myasnikova, Member of the European Parliament, European Parliament’s Committee on Environment and Social Affairs, Vice-President, Disability Intergroup at the European Parliament in conversation with Mr Danielo Bo, Director, European and International Advocacy, EURORDIS-Rare Diseases Europe
   • Dr. Ana Rath, International Advocacy, EURORDIS-Rare Diseases Europe
   • Ms Avril Daly, Associate Director of Public Policy, IFPMA
   • Ms Irina V. Myasnikova, Member of the European Parliament, European Parliament’s Committee on Environment and Social Affairs, Vice-President, Disability Intergroup at the European Parliament in conversation with Mr Danielo Bo, Director, European and International Advocacy, EURORDIS-Rare Diseases Europe
   • Ms Yukiko Nishimura, President and CEO, Canadian Organization for Rare Disorders (CORD); Former Chair, International Rare Disease Research Consortium (IRDiRC)
   • Ms Lauren Barredo, International Advocacy, EURORDIS-Rare Diseases Europe
   • Ms Durhan Wong-Roger, President and CEO, Canadian Organization for Rare Disorders (CORD); Former Chair of the Governing Board, International Alliance of Patients’ Organizations (IAP0)

3. **Lunch Break:**

   • Buffet to be served by the stairs behind the left side of the Vienna Café

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**Afternoon Plenary:**

4. **The Way Forward: Acting Globally From Within the UN SDGs**

   • Mr Durhan Wong-Roger, President and CEO, Canadian Organization for Rare Disorders (CORD); Former Chair of the Governing Board, International Alliance of Patients’ Organizations (IAP0)
   • Ms Yukiko Nishimura, President and CEO, Canadian Organization for Rare Disorders (CORD); Former Chair, International Rare Disease Research Consortium (IRDiRC)
   • Ms Lauren Barredo, International Advocacy, EURORDIS-Rare Diseases Europe
   • Ms Durhan Wong-Roger, President and CEO, Canadian Organization for Rare Disorders (CORD); Former Chair of the Governing Board, International Alliance of Patients’ Organizations (IAP0)

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**Closing Session:**

1. **How to Further Carry the Patients’ Voices at the Global Level to Deliver Change?**

   • Ms Durhan Wong-Roger, President and CEO, Canadian Organization for Rare Disorders (CORD); Former Chair of the Governing Board, International Alliance of Patients’ Organizations (IAP0)

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**CLOSING SESSION:**

17:30-18:00