

Under the patronage of  
**Queen Silvia of Sweden**



And

**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**



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

Agrenska 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.



[www.agrenska.se](http://www.agrenska.se)



[www.eurordis.org](http://www.eurordis.org)



[www.rarediseasesinternational.org](http://www.rarediseasesinternational.org)



[ngocommitteerarediseases.org](http://ngocommitteerarediseases.org) [@ngorarediseases](https://twitter.com/ngorarediseases)

11 November 2016



NGO COMMITTEE FOR  
**RARE DISEASES**

United Nations, New York

Graphic design www.FabienNail.com



# The Global Gathering for Rare Diseases

INAUGURATING  
THE NGO COMMITTEE  
FOR RARE DISEASES

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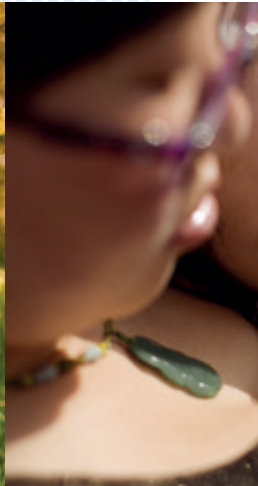
Friday 11 November 2016  
Conference Room 8 (GA-1B-CR08),  
United Nations, New York (NY 10017)

Morning Plenary: 10:00 to 13:30

KEYNOTE  
ADDRESSES

10:00-11:00

- 1 The United Nations and Civil Society: CoNGO and CoNGO Committees**  
**Mr Cyril Ritchie**, President of CoNGO 2011-2018
- 2 Public Health in the Mandate of the United Nations Economic and Social Council**  
**Mr Navid Hanif**, Director, Office for ECOSOC Support and Coordination, UN Department of Economic and Social Affairs (DESA)
- 3 Rare Diseases: A Common Cause at the Global Level**  
**Mr Anders Olauson**, Chairman, Ågrenska
- 4 How It All Started: The Contribution of the NGO Community to Advancing the Cause of Rare Diseases**
  - + **Ms Abbey S. Meyers**, President Emeritus, National Organization for Rare Disorders (NORD)
  - + **Mr Terkel Andersen**, President of the Board of Officers, EURORDIS-Rare Diseases Europe; Chairman of the Board, Danish Hemophilia Society
  - + **Prof Min-Chieh Tseng**, Founder, Taiwan Foundation for Rare Disorders; Dean, College of Social Sciences, National Taipei University



PANEL  
DEBATE 1

11:00-13:30

THE GLOBAL  
STATE OF PLAY OF  
RARE DISEASES

Moderator:  
**Mr Yann Le Cam**,  
Chief Executive,  
EURORDIS-Rare  
Diseases Europe;  
Council Member,  
Rare Diseases  
International (RDI)

- 5 A Call for Global Action Coming from Civil Society**  
**Mr Yann Le Cam**, Chief Executive, EURORDIS-Rare Diseases Europe; Council Member, Rare Diseases International (RDI)
- 6 Tackling Rare Diseases Internationally Through National and Regional Strategies**
  - + **Europe** ▶ **Ms Avril Daly**, Vice-President of the Board of Officers, EURORDIS-Rare Diseases Europe; Chief Executive, Retina International
  - + **North America** ▶ **Mr Paul Melmeyer**, Associate Director of Public Policy, National Organization for Rare Disorders (NORD)
  - + **Latin America** ▶ **Ms Migdalia Denis**, Founder, Venezuelan Society for Pulmonary Hypertension; Governing Board Member, International Alliance of Patients' Organisations (IAPO)
  - + **Russia** ▶ **Ms Irina V. Myasnikova**, President, Interregional Public Organisation « Help for Patients with Cystic Fibrosis »; Co-Chair, All-Russia Patients Union
  - + **Middle East and Central Asia** ▶ **Mr Sirous Eftekhari**, International Affairs, Rare Diseases Foundation of Iran (RADOIR)
  - + **Africa** ▶ **Ms Hawa Dramé**, Founder, Fondation International Tierno et Mariam (FITIMA), Burkina Faso and Guinea
  - + **Japan** ▶ **Ms Yukiko Nishimura**, President, ASrid (Japanese Advocacy Service for Rare and Intractable Diseases)
  - + **China** ▶ **Ms Rachel Yang**, Director of International Affairs, Chinese Organization for Rare Disorders (CORD)
  - + **Malaysia** ▶ **Ir Lee Yee Seng**, President, Malaysia Lysosomal Diseases Association
  - + **Australia** ▶ **Ms Megan Fookes**, Founder, Rare Voices Australia; Council Member, Rare Diseases International
- 7 Tackling Rare Diseases Internationally Through Bottom-Up Diagnosis and Care Strategies**
  - + **Mr Lieven Bauwens**, Secretary-General, International Federation for Spina Bifida and Hydrocephalus (IF)
  - + **Mr Alain Weill**, President of the Board, World Federation of Hemophilia (WFH)
  - + *in conversation with* **Ms Vidhya Ganesh**, Deputy Director, Programme Division, United Nations Children's Fund (UNICEF)

Lunch Break: 13:30 to 14:30

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

Afternoon Plenary: 14:30 to 18:00

PANEL  
DEBATE 2

14:30-17:30

THE WAY  
FORWARD:  
ACTING GLOBALLY  
FROM WITHIN THE  
UN SDGs

Moderator:  
**Ms Durhane Wong-Rieger**,  
President and CEO,  
Canadian Organization  
for Rare Disorders  
(CORD); Council  
Member, Rare  
Diseases International  
(RDI); Former Chair  
of the Governing  
Board, International  
Alliance of Patients'  
Organisations (IAPO)

CLOSING  
SESSION

17:30-18:00

- 8 How to Further Carry the Patients' Voice at the Global Level to Deliver Change?**  
**Ms Durhane Wong-Rieger**, President and CEO, Canadian Organization for Rare Disorders (CORD); Council Member, Rare Diseases International (RDI) ); Former Governing Board Chair, International Alliance of Patients' Organisations (IAPO)
- 9 The UN Sustainable Development Goals (SDGs): Implications for Health in General and Rare Diseases in Particular**
  - + **Ms Lauren Barredo**, Manager, Thematic Group on Health, UN Sustainable Development Solutions Network (SDSN)
  - + **Dr Nata Menabde**, Executive Director, WHO Office at the United Nations, New York
  - + *in conversation with* **Mr Jean-Louis Roux**, Public Affairs Director, European and International Advocacy, EURORDIS-Rare Diseases Europe
- 10 Bringing the SDGs to Life: Spotlight Examples of Where the Rare Disease Community Can Make a Contribution**
  - + **Disability and Gender** ▶ **Ms Maria Montefusco**, Secretary of the Council of Nordic Cooperation on Disability, Nordic Center of Welfare and Social Issues *in conversation with* **Dr Gustavo Gonzalez-Canali**, Senior Advisor, UN Coordination Division, UN WOMEN
  - + **Education** ▶ **Ms Gunilla Jaeger**, Psychologist, Ågrenska
  - + **Employment, Inclusion and Poverty** ▶ Video testimonial by **Mr Marek Plura**, Member of the European Parliament, European Parliament's Committee on Employment and Social Affairs; Vice-President, Disability Intergroup at the European Parliament *in conversation with* **Ms Daniela Bas**, Director, Division for Social Policy and Development (DSPD), UN Department of Economic and Social Affairs (DESA)
  - + **A Holistic Perspective** ▶ **Mr Tenu Avafia**, Human Rights, Law and Treatment Access, HIV, Health and Development Group, United Nations Development Programme (UNDP)
- 11 Avenues for Global Action: Mobilising all stakeholders in the rare disease community worldwide on the road to 2030**
  - + **IRDiRC: How Can International Collaboration Accelerate Research Advancements?** **Dr Christopher P. Austin**, Director, National Center for Advancing Translational Sciences (NCATS); Chair, International Rare Disease Research Consortium (IRDiRC)
  - + **IFPMA: How Can the Pharma and Biotech Industry Help Translate Scientific Opportunities into Accessible and Affordable Treatments?** **Dr Philip Vickers**, Global Head of Research and Development, Shire *on behalf of the International Federation of Pharmaceutical Manufacturers and Associations (IFPMA)*
  - + **OrphaNet: How Can International Classification of Rare Diseases, International Encyclopedias and Resource Listings Enhance Research and Clinical Excellence?** **Dr Ana Rath**, Director, INSERM US14-OrphaNet
  - + **ICORD: How Can A Cycle of Multi-Stakeholder Conferences Stimulate Dialogue and Actions in Different Parts of the World?** **Mr John Forman**, Past-President, International Conference on Rare Diseases and Orphan Drugs (ICORD)

- 12 Introducing the NGO Committee for Rare Diseases and its Founding Act « Rare Diseases and the UN Sustainable Development Goals »**  
**Mr Anders Olauson**, Chairman, Ågrenska
- 13 Closing Keynote Addresses**  
with an official statement from **H.E. Prime Minister Joseph Muscat and the Government of the Republic of Malta** on the eve of the Maltese Presidency of the Council of the European Union in 2017