Founding Act

« Rare Diseases and the UN Sustainable Development Goals »

New York City, Friday 11 November 2016

We, the undersigned participants to the inaugural « Global Gathering for Rare Diseases », proclaim and endorse the following statements:

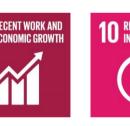
- Each of the 6,000 repertoried rare diseases affects a very small population locally. All together, however, they represent an international public health issue.
- The 350 million persons living with a rare disease worldwide are facing common challenges across diseases and across borders that affect all parts of their lives at once.
- No one country, no one continent alone can solve the problems posed by rare diseases.
- Experience shows that actions are possible and effective. Common national policies and international collaboration can address these challenges.
- Scientific, medical, technological, social opportunities will be high in the next 20 years. Patients, NGOs and other stakeholders are committed and aligned for partnership.
- Rare diseases fit within the objectives from several UN SDGs













and can significantly contribute to their achievement.

The NGO Committee for Rare Diseases will catalyse all efforts towards the delivery of the SDGs in support of rare diseases, and towards the recognition and integration of rare diseases in all relevant future global policy and initiatives of the United Nations and its agencies.

