

*RDI has been advocating since 2017 for rare diseases to be recognised in relevant bodies of the United Nations*

### **World Health Organization**

[Oral Statement on Rare Diseases at WHO 71st World Health Assembly](#), May 23, 2018 in Geneva

Submitted with Thalassaemia International Federation, World Federation of Hemophilia, International Alliance of Patients' Organisations and March of Dimes  
[Read article and watch video](#)

### **Non Communicable Diseases**

Submission to the [web-based consultation of the WHO Independent High-level Commission on NCDs](#) on May 16, 2018

RDI Council Members Durhane Wong Rieger and Lisa Phelps participated in UN NCD Civil Society Hearing in New York on July 5<sup>th</sup>, 2018

### **Human Rights**

**Rare Disease Contribution to Report on Health and Sustainable Development Goals from the Human Rights Approach** (OHCHR) SDGs and Health

Submitted with the NGO Committee for Rare Diseases at Human Rights Council 38th Session, June 18 – July 6, 2018 in Geneva.

[More information](#) on NGO Committee for Rare Diseases website

**Official Written Statement** [The Human Rights of People living with a Rare Disease](#) (based on Contribution to report on Health and SDGs by OHCHR)

Submitted with Thalassaemia International Federation, Agrenska Foundation and International Federation for Hydrocephalus and Spina Bifida

Presented at Human Rights Council 38th Session, June 18 – July 6, 2018 in Geneva

### **Disability**

**Rare Disease Contribution to Report of Special Rapporteur on the Right of People with Disabilities on the right of persons with disabilities to the highest attainable standard of health**, on March 30, 2018

Submitted with NGO Committee for Rare Diseases

[More information](#) on NGO Committee for Rare Diseases website

Paloma Tejada, Director of RDI, attended the Expert group meeting to inform the report on 15 & 16 May at the United National Office of Geneva)

Report to be presented by Special Rapporteur, Catalina Devandas, at 73rd UN General Assembly, Third Committee, October 2018

**Oral Statement** at Conference of States parties to Convention on the Rights of People with disabilities in New York – June 2018

[Video of the Statement on NGO Committee for Rare Diseases website](#)