PRESS RELEASE

Event: The right to health – making rare diseases a global health priority

#rdiGeneva

10 February 2017, Geneva – A-first-of-its-kind event takes place today in Geneva to bring together international experts in the fields of public health, human rights, scientific research, patient advocacy and the health industry to discuss why and how **rare diseases should be part of the global health agenda**.

Over 100 participants at the Rare Diseases International policy event '**The Right to Health: The Rare Disease Perspective**' are exploring ways to address inequality and improve access to health for the estimated 300 million people living with a rare disease across the world.

Follow the event live on Twitter via **#rdiGeneva**.

Held to mark the occasion of Rare Disease Day 2017, the event is organised in partnership with the BLACKSWAN Foundation and EURORDIS-Rare Diseases Europe. It focuses on the crucial role international collaboration plays in promoting rare diseases as a global public health and research priority, in line with the spirit of the United Nations' 2030 Sustainable Development Agenda of '*leaving no one behind*'.

Participants are discussing how this international cooperation is vital to incentivise research and innovation, to increase access to diagnostics, medicines and treatments, and to ensure rare diseases are integrated into Sustainable Development Goal (SDG) number three to 'ensure healthy lives and promote well-being for all at all ages'.

The event is organised in the wake of the third International Rare Disease Research Consortium (IRDiRC) Conference in Paris.

Today's discussions will build on the IRDiRC goals, as well as the 2030 Sustainable Development Agenda, the conclusions of the UN High-Level Panel on Access to Medicines, a statement made by Administrator of the UN Development Programme Helen Clark, and the work of the recently launched NGO Committee for Rare Diseases, which is committed to catalysing all efforts towards the delivery of the UN SDGs in support of rare diseases.

Key speakers at today's event include:

- **Christopher P. Austin**, Chair, International Rare Disease Research Consortium (IRDiRC), National Institutes of Health, USA

- **Peter Beyer**, Senior Advisor, Public Health, Innovation and Intellectual Property, Department of Essential Medicines and Health Products, World Health Organization
- **Ruth Dreifuss**, Co-Chair of the United Nations Secretary General's High-level Panel on Access to Medicines, former President of the Swiss Confederation
- **Dainius Pūras**, United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Office of the UN High Commissioner for Human Rights
- **Maria Luisa Silva**, Director of UN Development Program (UNDP) Office in Geneva

Patient representatives from around the world will also participate to illustrate the importance of patient input in efforts to make rare diseases a global health priority:

- **Hawa Dramé,** Founder, Fondation Internationale Tierno et Mariam (FITIMA), Burkina Faso and Guinea
- **Christina Fasser,** President, Retina International & Vice-Chair, ProRaris
- **Jim Green**, President, International Niemann-Pick Disease Alliance
- **Ramaiah Muthyala,** Founder & President, Indian Organization for Rare Diseases
- **Durhane Wong-Rieger,** President and CEO, Canadian Organization for Rare Disorders; Chair, Rare Diseases International

The event is initiated by patients through Rare Diseases International, under the patronage of the Federal Councillor Alain Berset, Head of the Swiss Federal Department of Home Affairs, and with the participation of the International Rare Diseases Research Consortium, the NGO Committee for Rare Diseases, Orphanet and ProRaris.

It takes place in Geneva, the main hub of global health governance, which hosts the United Nations and the headquarters of the World Health Organization.

###

Press contact:

Paloma Tejada
Senior Manager, Rare Diseases International
+41 763604725
paloma.tejada@eurordis.org

About Rare Diseases International

Rare Diseases International is a EURORDIS-led initiative that brings together national and regional rare disease patient organisations from around the world, as well as international rare disease-specific federations to create the global alliance of rare disease patients and families. RDI's mission statement is to be a strong common voice on behalf of the people living with a rare disease around the world, to advocate for rare diseases as an international public health priority, and to represent/ enhance the capacities of its members. Read the RDI Joint Declaration 'Rare Diseases: An International Public Health Priority'.

Visit www.rarediseasesinternational.org and follow @rarediseasesint.

About Rare Disease Day

EURORDIS-Rare Diseases Europe and its Council of National Alliances launched Rare Disease Day in 2008. Held on the last day of February each year, it seeks to raise awareness of the impact that rare diseases have on the lives of patients and those who care for them. What began as a European event quickly became international in scope, with participants from more countries joining each year.

Since Rare Disease Day began, thousands of events have been held throughout the world, reaching hundreds of thousands of people. The political momentum resulting from the Day has also served advocacy purposes, contributing to the advancement of EU policies on rare diseases and to the creation of national plans for rare diseases in a number of EU Member States. Visit RareDiseaseDay.org, follow Rare Disease Day on Twitter and Facebook.

About rare diseases

The European Union considers a disease as rare when it affects less 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, and an estimated 300 million people across the world. 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.