

THEME 2

OUR VALUES, OUR RIGHTS, OUR FUTURE: SHIFTING PARADIGMS TOWARDS INCLUSION

THEME LEADERS:

Maria Montefusco, President, Rare Diseases Sweden, Sweden

Valentina Bottarelli, Public Affairs Director and Head of European and International Affairs, EURORDIS

THEME SUPPORT :

Clara Hervas, Public Affairs Manager, European and International Affairs, EURORDIS

THEME DESCRIPTION:

Evidence demonstrates that people living with a rare disease and their families continue to face serious every day and social inclusion challenges. Rare diseases ensue in a high level of psychological, social and economic vulnerability and are detrimental to people's active participation in society.

This interlinkage between rarity, vulnerability, inequalities and social exclusion means that there is space for the integration of rare disease strategies into the broader human rights' agenda, and the health and development efforts at global level, with clear opportunities to contribute to the United Nations Agenda 2030: the Sustainable Development Goals (SDGs). This goal-based framework was agreed in 2015 by all UN Member States with the clear principle to "leave no one behind". In this sense, the SDGs are interdependent, universal goals that aim to address global challenges (such as poverty, health and climate).

The synergies between the SDGs and rare diseases have been acknowledged in different events, reports and texts of the UN, and there is momentum for international commitments for the benefit of persons living with a rare disease. In particular, the rare disease community has voiced the need to be included in efforts to achieve Universal Health Coverage (UHC) (as part of SDG 3 which focuses on health), as well as in efforts to ensure non-discrimination on the basis of health or disability status (as part of SDG 10 on reducing inequalities, or SDG 8 on decent work for example).

This theme will look at these ongoing advances in international advocacy and discuss the significance they have for different stakeholders of the rare disease community. A key goal of the theme will be to discuss how the rare disease community can translate those global commitments and aspirations into concrete regulatory practices and policies in the national context, which will have a real impact on the daily lives of those affected. Ongoing trends like reduced funding for human rights, an increasingly challenging political and social space, a debilitation of the values of solidarity and equity, and a shrinking space for civil society will be part of the debate, but the overall objective of the theme will be to identify the best practices and potential new practices that prove the value of investing in human rights and inclusion.

PRE-RECORDED SESSION: (Available on demand)

Getting our rights 'right': An international framework for rare diseases

Why should European citizens be concerned by the decisions being taken at the United Nations? Why should international collaboration continue to be fostered in the field of rare diseases? What sort of traction and impact can international frameworks have at the national level? To explore these questions, this session will first frame rare diseases as a policy priority, showcasing the EU approach and its framework established for addressing this issue. The session will then move on to frame rare diseases within the global human rights and Sustainable Development Goals (SDGs) agendas and present the advances made so far in international advocacy in engaging the United Nations bodies and agencies (UN General Assembly, Office of the High Commissioner for Human Rights, Human Rights Council...). Finally, the session will explore how to continue the progress towards a global agenda that addresses the needs of persons living with a rare disease and encourages enforcement nationally, through tools such as UN resolutions.

Chair: Yann Le Cam, Chief Executive Officer, EURORDIS-Rare Diseases Europe

Speakers:

Anders Olauson, Chair, NGO Committee for Rare Diseases

Dr. Durhane Wong-Rieger, Canadian Organization for Rare Disorders

Raquel Peck, Senior Advisor and Former CEO of World Hepatitis Alliance, USA

Todd Howland, Chief of the Development and Economic and Social Issues Branch, UN OHCHR

SESSION 0201: Thursday 14 May 2020, 14:45 – 16:15

UHC: from political commitment to reality for all

What is the value of Universal Health Coverage? What will the impact be in Europe: in terms of population, of services provided and of percentage of coverage? How will the EU implement the international commitments on UHC? Do national strategies on rare diseases successfully ensure the rights to health of persons living with a rare disease? How are patient's rights in cross-border care implemented across Europe and do they actually ensure access to health when this is not provided at country level? This session will look at these sorts of questions during a panel discussion on our current system and whether it may be outdated and in need of a paradigm shift. Possible trends like increased social investment, early intervention and prevention and promotion and the consequences of this on the balance between primary and secondary care will be part of the discussion.

Chair: Dr. Nata Menabde, Executive Director, WHO Office at the UN

Speakers:

Ilona Kickbusch, Director of the Global Health Programme, Graduate Institute of International and Development Studies, Geneva

Matt B. Johnson, Rare Diseases International Healthcare Advisor, WHO Collaborative Global Network for Rare Diseases, Germany

Martin Seychell, Deputy Director-General for Health and Food Safety, DG SANTE, European Commission, Belgium

Vytenis Andriukaitis, WHO Special Envoy for the European Region, Lithuania

SESSION 0202: Thursday 14 May 2020, 16:45 – 18:15

Holistic Care for People Living with Rare Diseases: The Future is Now

“The specific nature of rare diseases also calls for a holistic, comprehensive and multi-disciplinary response, deeply grounded by essence in a human rights vision” (Dainius Puras, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of health). This session looks at what holistic care means in practice for persons living with a rare disease from a human rights framework and a societal point of view, rather than solely in terms of provision. It will particularly focus on the opportunities that holistic care offers, but will also look at the risks or hurdles that may be encountered to fully implement this. The session could also be an opportunity to look at how rights are interpreted in different scenarios, and therefore enshrined into and enforced (or not) within different models of care, which may depend on the direction that society as a whole chooses to take.

Chair: Robert Hejdenberg, CEO, Agrenska, Sweden

Speakers:

Rebecca Tvedt Skarberg, Advisor, Osteogenesis Imperfecta Federation Europe (OIFE), Norway

Dr. Encarna Guillén, Head of Unit of Medical Genetics, Paediatric ward, Hospital Clínico Universitario Virgen de la Arrixaca, Spain

Dr. Cecilia Gunnarsson, Division of Clinical Genetics, Department of Clinical and Experimental Medicine, University Hospital, Linköping University, Linköping, Sweden

SESSION 0203: Friday 15th May 2020, 11:30 – 13:00

Rare and Equal: Ensuring Non-Discrimination on the Basis of Health and Disability

People living with a rare disease often face discrimination and stigma based on their health status or chronic condition, experiencing unequal treatment in a number of areas ranging from access to education, employment, leisure and other essential support services. This is aggravated when the illness is invisible or changing. This session will present the major figures on this issue as well as personal stories and will look at the ways of enforcing these persons’ rights (CRPD articles 5, EU Charter of Fundamental Rights, European Pillar of Social Rights), particularly by ensuring appropriate regulatory processes and making use of existing tools.

Chair: Maria Montefusco, President, Rare Diseases Sweden

Speakers:

David Lega, Member of the European Parliament (MEP), Sweden

Jana Popova, EAMDA Executive Committee, Bulgarian Association for Neuromuscular Diseases & EPF Youth Group, Bulgaria

Inmaculada Placencia Porrero, Senior Expert Social Affairs, European Commission, DG for Employment, Social Affairs and Inclusion, Unit for Disability and Inclusion

Alarcos Cieza, Unit Head, Sensory functions, Disability and Rehabilitation, World Health Organisation

SESSION 0204: Friday 15th May 2020, 14:00 – 15:30

Reaching Future Scenarios: From Accidental Progress to Success by Design

This session will present the scenarios currently being developed under the Rare2030 project and the different policy options associated to them. The session aims to be interactive, engaging the panellists and audience in a back-casting exercise and a vote on the preferred policy options.

Chair: Hans Winberg, Secretary General, Leading Health Care, Sweden

Speakers:

Terkel Andersen, President EURORDIS-Rare Diseases Europe

Rebecca Tvedt Skarberg, Advisor, Osteogenesis Imperfecta Federation Europe (OIFE), Norway

Prof. Milan Macek, Dept of Biology and Medical Genetics, Charles University and Orphanet Czech Republic

Anna Krohwinkel, Leading Health Care, Sweden