



# Rare Diseases 360°

Collaborative Strategies  
to leave no-one behind

9th European Conference  
on Rare Diseases and Orphan Products

**10-12 May 2018 Vienna**

Messe Wien Exhibition & Congress Center

## OPENING SESSION AGENDA

Friday, 11<sup>th</sup> May 2018 - 09:00 - 09:45

### WELCOME ADDRESS AND OPENING REMARKS

09.00 - 09.20

- **Terkel Andersen**, President, EURORDIS-Rare Diseases Europe
- **Magdalena Daccord**, Associate Director, Head Of Operations EMEA - DIA
- **Ana Rath**, Director, Orphanet
- **Rainer Riedl**, President, Pro Rare Austria

### KEYNOTE ADDRESSES

09.20 - 09.45

- **Beate Hartinger-Klein**, Austrian Federal Minister of Health and Women's Affairs
- Video message: **Vytenis Andriukaitis**, European Commissioner for Health and Food Safety
- **Martin Seychell**, Deputy Director-General, Directorate-General for Health and Food Safety, European Commission

### COFFEE BREAK

09.45 - 10.15

## PLENARY SESSION AGENDA

Friday, 11<sup>th</sup> May 2018 - 10:15 - 12:30

### WELCOME & INTRODUCTION

10:15 - 10:30

**Justina Januševičienė**, Executive for the development of health care technologies and innovations, Lithuanian University of Health Sciences and immediate past Director of the Healthcare resources and innovation management department, Ministry of Health, Lithuania

## INSPIRATIONAL SPEAKER

10:30 – 10:45

**Dr Rüdiger Krech**, Director, Universal Health Coverage and Health Systems Office of the Assistant Director-General, World Health Organization

## PATIENT TESTIMONY

10:45 – 10:55

**Maria Prähofer**, living with MPS IVA, Morbus Morquio

## VIDEO PRESENTATIONS

10:55 – 11:05

**Daniela Bas**, Director, Division for Social Policy and Development Department of Economic and Social Affairs, United Nations

## RARE DISEASE PATIENTS' NEEDS AND GOALS

11:05 – 11:30

**Lene Jensen**, Chief Executive Officer, Rare Diseases Denmark

## RARE DISEASE POLICY PRIORITIES FOR THE FUTURE

PANEL DISCUSSION

11:30 – 12:30

Moderator: **Yann Le Cam**, EURORDIS-Rare Diseases Europe

Panellists:

- **Martin Seychell**, Deputy Director-General, Directorate-General for Health and Food Safety, European Commission
- **Dr Rüdiger Krech**, Director, Universal Health Coverage and Health Systems Office of the Assistant Director-General, World Health Organization
- **Nathalie Moll**, Director General, EFPIA
- **Holm Graessner**, Coordinator Solve-RD and ERN-RND
- **Lene Jensen**, Rare Diseases Denmark
- **Dr. Christa Wirthumer-Hoche**, Head of Austrian Medicines and Medical Devices Agency; Chair, European Medicines Agency's (EMA) Management Board

## CLOSING PLENARY SESSION AGENDA

Saturday, 12<sup>th</sup> May 2018 - 16:15 – 17:00

## TAKE HOME REMARKS

16:15 – 17:00

- **Theme 1: Lauren Roberts**, Director of Support, Genetic Alliance UK, National Coordinator, Swan UK, UK
- **Theme 2: Violeta Stoyanova-Beninska**, COMP Member, Chair of National Scientific and Regulatory Advice, Netherlands
- **Theme 3: Julian Isla**, Data and Artificial Intelligence Resource Manager, Microsoft and Dravet Syndrome European Federation (DSEF), Spain
- **Theme 4: Ursula Holtgrewe**, Head of Work & Equal Opportunities, Zentrum für Soziale Innovation, Austria
- **Theme 5: Michael Schlender**, Professor of Health Economics, University of Heidelberg, Germany
- **Theme 6: Durhane Wong-Rieger**, President & CEO Canadian Organization for Rare Disorders, Chair of Rare Diseases International, Founder of the Asia Pacific RD Alliance (APARDO), Canada