OPENING SESSION AGENDA

Friday, 15 May 2020 - 08:30 - 10:00

The Opening and Plenary Sessions will be simultaneously interpreted from English into 2 languages:

French
German

MODERATOR	Lise Murphy, Patient Advocate, Marfanföreningen (Swedish Marfan Association)
WELCOME ADDRESS	Terkel Andersen, President, EURORDIS-Rare Diseases Europe
& OPENING REMARKS	Ana Rath, Director, Orphanet
	Maria Montefusco, President, Rare Diseases Sweden
KEYNOTE ADDRESSES	Representative from the Swedish Ministry of Health
	Representative from the European Commission
	Dr. Lennart Christiansson, Chair, ERN Board of Member States

PLENARY SESSION AGENDA

Friday, 15 May 2020 - 10:00 - 12:00

The Opening and Plenary Sessions will be simultaneously interpreted from English into 2 languages:

French
German

KEYNOTE ADDRESSES

Discoveries for the Benefit of Man: Lessons from the Past and Hope for the Future

Professor Anna Wedell, Member and Former Chair of the Nobel Committee for Physiology or Medicine, Sweden

Love, Support, Encouragement and Demands – Being a Policy Maker with a Rare Disease

David Lega, Member of the European Parliament, Sweden

Life languages and red flags in the red sand

Dr Gareth Baynam, Clinical Geneticist, Genetic Services of Western Australia

We are all Preparing the Future of Someone Else

Didier Schmitt, Coordinator Directorate of Human and Robotic Exploration, European Space Agency, Netherlands

RARE 2030 FORESIGHT

Rare 2030 Overview

Prof. Milan Macek, Motol University Hospital and Charles University, Prague

Video: Rare 2030 "What If" Scenarios

Outcomes of the Rare Barometer Voices Survey

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

Audience Voting