



XIII ICORD Meeting Stockholm, Sweden 20-21 September 2018

Theme: Fulfilled and Remaining Unmet Needs for Rare Diseases: The Future of ICORD

Venue: The BioClinicum Building, Karolinska University Hospital Solna, Stockholm

DAY 0: Wednesday 19 September

15.30-19.00 Board meeting (ICORD Board Members only)

DAY 1: Thursday 20 September

08.30-09.00 Registration

09.00-09.20 **Opening session & Welcome address** (Manuel de Posada and Ann Nordgren, ICORD; Lena Löqvist, MSc, PhD, the Swedish National Board of Health and Welfare)

INTRODUCTION: FROM THE START OF ICORD TO THE FUTURE

09.20-09.40 Achievements in Rare Diseases and the History of ICORD (Jan-Inge Henter)

09.40-10.20 Keynote: Unmet Needs today in Rare Diseases (tbd)

10.20-10.50 Coffee/Tea break

GLOBAL IMPACT OF ICORD CONFERENCES

10.50-11.00 Impact of ICORD Conferences: Summary (Virginia Llera, Argentina)

11.00-11.50 Impact of ICORD Conferences across Continents
(Domenica Taruscio, Italy; Yukiko Nishimura, Japan; Albina Makaeva, Russia; Mario Alanis, Mexico; Kelly du Plessis, South Africa)

11.50-12.05 Call to Action: From Yukawariso declaration to Protea declaration. (Steve Groft)

12.05-13.20 Lunch

RARE DISEASES INTERNATIONAL

13.20-14.00 Rare Diseases International (RDI) (Yann Le Cam, Durhane Wong-Rieger)

OTHER GLOBAL RARE DISEASE ACTIONS

14.00-14.20 United Nations Non-Governmental Organization (NGO) Committee for Rare Diseases (Anders Olason)

14.20-14.50 Undiagnosed Diseases Network International (UDNI) & Karolinska Undiagnosed Disease Program (UDP) (Helene Cederroth, Ann Nordgren, Anna Wedell)

14.50-15.20 Rare Diseases Research in a Global Perspective (IRDiRC Global Research Program) & E-Rare (Daria Julkowska)

- 15.20-15.50 Coffee/Tea break
15.50-16.10 Human Rights and Public Health on Rare Diseases
16.10-16.30 How to implement rare diseases plans in developing countries
(Domenica Taruscio/Rumen Stefanov)

THE FUTURE DIRECTION OF ICORD

- 16.30-16.45 Introduction (John Forman)
16.45-17.15 Working group report (Catarina Edfjäll)
17.15-17.30 ICORD Activities Carried out during 2018 (Manuel de Posada/Wills Hughes-Wilson)
17.30-17.45 Collaborating opportunity from UAE Genetic Diseases Association (tbd)
17.45-18.00 Possible Future ICORD Conferences (Emilio Roldán)

18.30- Conference Dinner

DAY 2: Friday 21 September

- 08.15-08.30 Ministry of Health of Israel and a Possible ICORD Conference (Hadar Yardeni)

THE ORGANIZATIONAL FUTURE OF ICORD

- 08.30-08.45 Alternative ICORD Organizational Scenarios after 2018 (Jan-Inge Henter)
08.45-10.00 Panel Discussion about the Organizational Future of ICORD

10.00-10.30 Coffee/Tea Break

GENERAL ASSEMBLY & CLOSING SESSION

- 10.30-12.30 General Assembly; open for members only (Manuel de Posada & Steve Groft)
12.30-13.00 **Closing Session** (Jan-Inge Henter, Manuel de Posada, Steve Groft)
13.00-14.00 Light lunch available
13.00-15.00 **Time (and rooms) available for networking and unofficial meetings**