



13th ICORD Meeting - Stockholm 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

Room: Auditorium Torsten N Wiesel, J3:04, Solnavägen 30, 171 64 Solna

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 Posada and Ann Nordgren, ICORD; Ulrika Vestin, Swedish Association of Local Authorities and Regions)

INTRODUCTION: FROM THE START OF ICORD TO THE FUTURE (Moderator: Ann Nordgren)

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 (Yann Le Cam; CEO EURORDIS)

10.20-10.50 Coffee/Tea break

GLOBAL IMPACT OF ICORD CONFERENCES (Moderator: Emilio Roldán)

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

11.00-11.45 Impact of ICORD Conferences across Continents (Virginia Llera, Latin America; Domenica Taruscio, Italy; Yukiko Nishimura, Japan; Albina Makaeva, Russia)

11.45-12.00 Call to Action: From Yukawariso Declaration to Protea Declaration. (Steve Groft)

12.00-13.30 Lunch (at *Glada Restaurangen*; address CMM, Anna Steckséns gata 18, 171 76 Solna)

RARE DISEASES INTERNATIONAL (Moderator: Wills Hughes-Wilson)

13.30-14.00 Rare Diseases International (RDI) (Paloma Tejada, Yann LeCam)

OTHER GLOBAL RARE DISEASE ACTIONS (Moderator: Fernando Royo)

14.00-14.30 Undiagnosed Diseases Network International (UDNI) & Karolinska Undiagnosed Disease Program (UDP) (Helene Cederroth, Ann Nordgren, Anna Wedell)

14.30-14.50 United Nations Non-Governmental Organization (NGO) Committee for Rare Diseases (Anders Olason)

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 (Manuel Posada)

16.10-16.30 Transposition and implementation of EU rare disease policy in Eastern Europe (Rumen Stefanov)



DAY 1 Thursday 20 September (Cont.)

THE FUTURE DIRECTION OF ICORD (Moderator: Jan-Inge Henter)

- 16.30-16.45 Introduction (John Forman)
16.45-17.15 Working group report (Wills Hughes-Wilson)
17.15-17.30 ICORD activities carried out during 2018 (Manuel Posada)
17.30-17.45 Collaborating opportunity from Rare Disease Foundation of Iran (Hamid Reza Edraki)
17.45-18.00 Possible Future ICORD Conferences (Emilio Roldán)

18.30- Conference Dinner

Restaurant *Svarta Räfven* ("the Black Fox"),
Aula Medica Building, 7th floor = top floor, Address: Nobels väg 6, 171 65 Solna

DAY 2: Friday 21 September

Auditorium Torsten N Wiesel, J3:04 (at the BioClinicum Building, Solnavägen 30, 171 64 Solna)

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

THE ORGANIZATIONAL FUTURE OF ICORD (Moderator: Désirée Gavhed)

- 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 (Moderator/Chair: Manuel Posada)

- 10.30-12.30 General Assembly; open for Members Only (Manuel Posada & Steve Groft)
12.30-13.00 **Closing Session** (Jan-Inge Henter, Manuel Posada, Steve Groft)

13.00-14.00 Light lunch available (at the conference venue)
13.00-15.00 Time (and rooms) available for networking and unofficial meetings