Preliminary program ICORD 2013 St Petersburg

Please visit the sponsor exhibitions 10-17 hrs, both days.

Day 1

08:30 Session 1: *Opening*
Chairman: Virginia Llera (ICORD President), Rumen Stefanov (ICORD Board member and ICORD 2013 local organizing committee), Svetlana Karimova (President Genetics, ICORD 2013 local organizing committee).
Welcome and introduction.
08:50 Domenica Taruscio (ICORD Past President). *ICORD history and aims*
09:15 Russian Ministry of Health or representative - *Welcome*

09:30 Plenary Conference
Coordinator: Virginia Llera (Argentina)
Paul Lasko, President of the International Rare Diseases Research Consortium (IRDiRC)

10:15 Break + poster session I

10:45 Session 2: Linking Global Efforts for Rare Diseases Research and Registries.
Coordinators: Stephen Groft (USA), Domenica Taruscio (Italy)
10:50 Steve Groft (ORDR, NIH, USA), *Patient Registries - A Global Response to Unmet Needs*
11:05 Domenica Taruscio (ISS, Italy), *European platforms: EPIRARE and RD-Connect*
11:20 Paul Ledger (GSK, UK), *Innovative collaborations models to fund discovery stage rare diseases research*
11:35 Q&A

11:45 Session 3: Primary Prevention, Modern Diagnostics and Screening for Rare Diseases
Coordinator: Yukiko Nishimura (Japan); Moderator: Emilio Roldán (Argentina)
11:50 Ann Nordgren (Associate Prof, Dept. of Clinical Genetics, Karolinska Institutet, Sweden): *Next Generation Sequencing for the diagnosis of Rare Diseases in clinical practice.*
12:05 Aliy Asanov (Professor, Dept. of Medical fields of genetics in the Moscow State University. Russia) Title TBD
12:20 Alberto Mantovani (Italy), *Primary prevention of congenital anomalies*
12:35 Tom Pulles (Global Medical Direction for Shire's MPS program) Title TBD
12:50 Q&A

13:00 Lunch
13:10 - 13:50 Hot Topic Conferences

14:00 Session 4: National Initiatives
Coordinator: Rumen Stefanov (Bulgaria)

14:05 Oleg Kvlividze (Georgian Foundation for Genetic and Rare Diseases, Georgia)
14:20 Uguz Ozbek (Turkey)
14:35 Vinciane Pirard (Public Affairs, Genzyme, The Netherlands)
14:50 Q&A

15:00 Working Groups in parallel sessions: "Seed Accelerators"
Coordinator: Désirée Gavhed (Sweden)

16:30 Break (during working group session)

17:20 General Assembly
Coordination: Manuel Posada (Spain)
Presentation of proposals for future meetings

19:20 end of day 1 activities ----------

20:00 Gala Dinner

Day 2

08:30 Session 5: Clinical Trials of Rare Diseases and Orphan Drugs and Repurposing of Existing Drugs.
Coordinators: Simon Day (UK) and Jan-Inge Henter (Sweden).
08:35 Simon Day (UK), *Statistical planning to get good evidence*
08:50 Steve Groft (NIH, USA). *Accelerating new treatments for rare diseases to be studied in clinical studies: Update from the National Center for Advancing Translational Sciences (NCAT) at NIH*
09:05 Tim Coté (USA). *Repurposing of drugs: How to use the existing drugs smarter?*
09:20 Michael Maschan (Moscow, Russia). *Experiences on running clinical trials on Rare Diseases in Russia*
09:35 Q&A

09:45 Session 6: Big ideas for small populations: incentives, regulatory flexibility and harmonization.
Coordinator: Tim Coté (USA)
09:50 Penny Bemis (Centric Therapeutics), *Specialty pharmaceuticals distribution and patient support*
10:05 Howard Yuwen (Alexion Therapeutics, USA), *U.S. Orphan Drug Development 30 Years*
10:20 Daria Julkowska (E-Rare Project Coordinator, France), *E-RARE - A Transnational Platform for Rare Diseases Research Funding*
10:35 Adam Heathfield (Pfizer, UK) Title TBD
10:50 Q&A

11:00 Break + poster session II

11:30 Session 7: Clinical Guidelines and Best Practices.
Coordinator: Manuel Posada (Spain)
11:35 Domenica Taruscio (ISS, Italy), *Rare Best practices: a platform for sharing best practices for the management of rare diseases*

11:50 J-I Henter (Karolinska Inst., Sweden), *Clinical Guidelines and Practices: Examples from International Collaboration in Clinical Practice.*
12:05 Nick Ah Mew (Children's National Medical Center, Rare Diseases Clinical Research Network, NIH, USA) title TBD
12:20 Q&A

12:30 Lunch
12:30 - 13:30 Hot Topic Conferences

13:45 Session 8: Health policy and National Plans for Rare Diseases.
Coordinator: Marlene Haffner (USA)
13:55 Manuel Posada (Instituto de Salud Carlos III, Spain), *Social-Economic Burden and Health-related Quality of Life in Patients with Rare Diseases in Europe (BURQOL-RD)*
14:10 Rumen Stefanov (Information Centre for Rare Diseases and Orphan Drugs, Bulgaria), *National Plans in Eastern European Countries*
14:25 Marcin Boruk (Health Canada, Canada), *Emerging Orphan Drug Policy in Canada*
14:40 Yukiko Nishimura (Tokyo University, Japan) title TBD

15:00 Session 9: Patient Priorities in Primary Prevention, Diagnosis and Clinical Care of Rare Diseases
Coordinator: John Forman (New Zealand)
15:05 Svetlana Karimova (National Association of Organization of Patients with Rare Diseases "Genetics", Russia)
15:20 Pablo Cure (GEISER Delegate from LA&C, Colombia)
15:35 Anders Olauson (Ågrenska Foundation)
15:50 John Forman (New Zealand Organisation for Rare Disorders)
16:05 Q&A

16:15 Break

17:00 Working groups conclusions
Coordinator: Désirée Gavhed

18:00 Closing session
Chair: V. Llera, M. Posada, J. Forman
Presentations of next meeting proposals

19:00 End of Meeting