

Agenda

THIRD INTERNATIONAL CONFERENCE ON RARE AND UNDIAGNOSED DISEASES

CeMM Research Center for Molecular Medicine
Vienna, Austria
February 18, 2016

- 9:00 Welcome
Kaan Boztug, William Gahl
Wilhelm Foundation (Helene and Mikk Cederroth)
- 9:10-9:20 Introductions
- 9:20-9:35 Goals of this meeting: Update, Sharing
Boztug, Gahl
- 9:35-10:00 Update on UDNI, Governance, Membership, Website, Journal?
Salvatore Marco, Florida Giovanna, Domenica Taruscio, Gahl
- 10:00-10:45 Updates from Various Centers (5 min; 0-3 slides)
UDN (Anastasia Wise)
Vienna (Kaan)
Italy (Domenica)
Australia (Gareth Baynam)
Japan (Kenjiro Kosaki)
Korea (Hyun-Young Park)
India (Ratna Puri)
- 10:45-11:15 Break (Wilhelm Foundation)**
- 11:15-12:00 More Updates
Spain (Manuel Posada)
Mayo (Steve Ekker)
Emory (Clyde Partin)
Eurordis (Virginie Bros-Facer)
NORD (Paul Melmeyer)
Telethon (Vincenzo Nigro)
Regeneron (Ale King and Claudia Gonzaga)

12:00-12:30	Open Discussion for others to update their efforts
12:30-1:30	Lunch (Wilhelm Foundation)
1:30-3:00	Options for Data Sharing Alexa McCray, UDN Coordinating Center David Adams Paul Lasko
3:00-3:30	Discussion
3:30-4:00	Break (Wilhelm Foundation)
4:00-5:00	Sustainability of the UDNI <ul style="list-style-type: none"> - Use and Outcomes Data - Administrative Requirements and Staff - Patient Recruitment - Measures of Success: Applications, Acceptances, Publications - Internet Links for Undiagnosed Diseases: GARD, CC, UDN, GINA, SWAN, INOD, etc. Steve Groft, William Gahl, others
5:00-5:30	Plans for the future; future meetings
6:30-9:00	Dinner at a Heuriger (courtesy of the Wilhelm Foundation)