

## Agenda Ana Airport Sibiu 4<sup>th</sup> – 7<sup>th</sup> October, 2018

- Day I**                    4<sup>th</sup> October      ARRIVALS
- Day II**                    5<sup>th</sup> October      CONFERENCE *Rare Stars: Giving hope, improving lives*
- 09:30 – 10:00    Registration of ALL participants
- 10:00 – 10:20    Opening/WELCOME    Dr. George Sinca, President ROLSDF
- 10:20 – 10:40    Launching e-book project Presentation Daniela Zlatea ROLSDF  
REMEMBER FRBL ALL #1 Campaign
- 10:40 – 11:00    Presentation performed by Dr. Simona Bucerzan, Regional Genetic Centre of Medical Genetics, Emergency Clinic Hospital Cluj
- 11:00 – 11:20    Presentation performed by Asist. Univ. Dr. Bogdan Chiș, Medical Clinic II, Regional Clinical Hospital Cluj
- 11:20 – 11:40    Coffee Break
- 11:40 – 12:00    European Reference Network: MetabERN  
Presentation performed by Mrs. Lut de Baere, BOKS Head, Metabolic Disaeses
- 12:00 – 12:20    Successful Collaborations Session II – Presentation performed by Mrs. Dorica Dan, President of RONARD, BOD of Prader Willi Association in Romania, BOD EURORDIS
- 12:40 – 13:00    Q&A Session
- 13:00 – 14:00    Lunch
- 14:00 – 15:00    Special Session with a Psychologist (*“Revive the sense of belonging of ROLSDF members”*)
- 15:30 - 16:30    ROLSDF Meeting with Members (I)  
1. Presentation of New Communication Platform of ROLSDF  
2. Encourage members to actively participate in the social launched campaign  
REMEMBER FRBL ALL 4#1
- 16:30 – 16:50    Coffee break
- 16:50 – 18:00    ROLSDF Meeting with Members (II)  
3. Awareness Campaigns Presentation of ROLSDF Partners for supporting it in social media  
4. Presentation of the movie project consisting in interviews with patients and care-partners and encouraging them to become part of the project
- 19:00                    GALLA DINNER
- DAY III**                    6<sup>th</sup> October      Marking the International Gaucher Day (THEME *Rare Stars: Giving hope, improving lives*)
- 10:00 – 13:00    Meeting with the members of the ROLSDF – Organized sightseeing of Sibiu and awareness activities for the large public  
Shooting session and VOX-es for revealing HOPE and LIFE
- 13:00 – 14:00    LUNCH in Sibiu
- 15:00 – 17:00    Interviews and Shooting session organized outdoors and indoors with members of ROLSDF
- 19:00                    Dinner
- DAY IV**                    Breakfast & Departures