

Draft Agenda - Workshop
Guiding Principles for Social Care of People Living with Rare Diseases
October 9-10, Frambu Resource Centre, Oslo, Norway

Wednesday, 8th: dinner will be provided at Frambu for all participants.

DAY 1: Thursday 9 October

08:45 Welcome to all participants, *by Dorica Dan, EURORDIS and Kjetil Ørbeck, Frambu*

09:00 EUCERD Joint Action, *by Victoria Hedley, Newcastle University*

09:20 Specialised Social Services and Integration of RDs into Social Policies: State of the Art, *by Raquel Castro, EURORDIS*

09:40 Introduction to the Workshop: context, theme, purpose, methodology, and expected outcomes *by Dorica Dan, EURORDIS and Raquel Castro, EURORDIS*

10:00 Coffee Break (15min)

10:15-10:45 Visit to Frambu Resource Centre

10:45-12:45 State of the Art of Social Care Pathways in MS:

France *by Christel Nourissier, Alliance Maladies Rares, EUROPLAN advisor and member of the Regional Committee for Rights and Autonomy of People Living with Disabilities*

Norway *by Ragnhild Øverland Arnesen, Prader-willi Association Norway; Stein Are Aksnes, General Director, Norwegian National Advisory Unit on Rare Disorders*

12:45 Lunch (1h)

13:45-15:45 State of the Art of Social Care Pathways in MS (cont.):

Italy *by Simona Belagambi, UNIAMO, EUROPLAN advisor*

Sweden *by Maria Montefusco fd Gardsäter, EUROPLAN advisor, Project Manager at Council of Nordic Cooperation on Disability*

15:45 Coffee Break (15min)

16:00-18:30 Group Discussions

19:30 networking dinner

DAY 2: Friday 10 October

08:45 Recap from day 1, *by Raquel Castro, EURORDIS*

09:00-10:30 Discussions in plenary

10:30 Coffee Break (15min)

10:45-12:45 Conclusions

12:45 Lunch (1h)

14:00 End of Workshop