



2nd EPIRARE Meeting

Participants: Partners, Advisory Board and invited experts

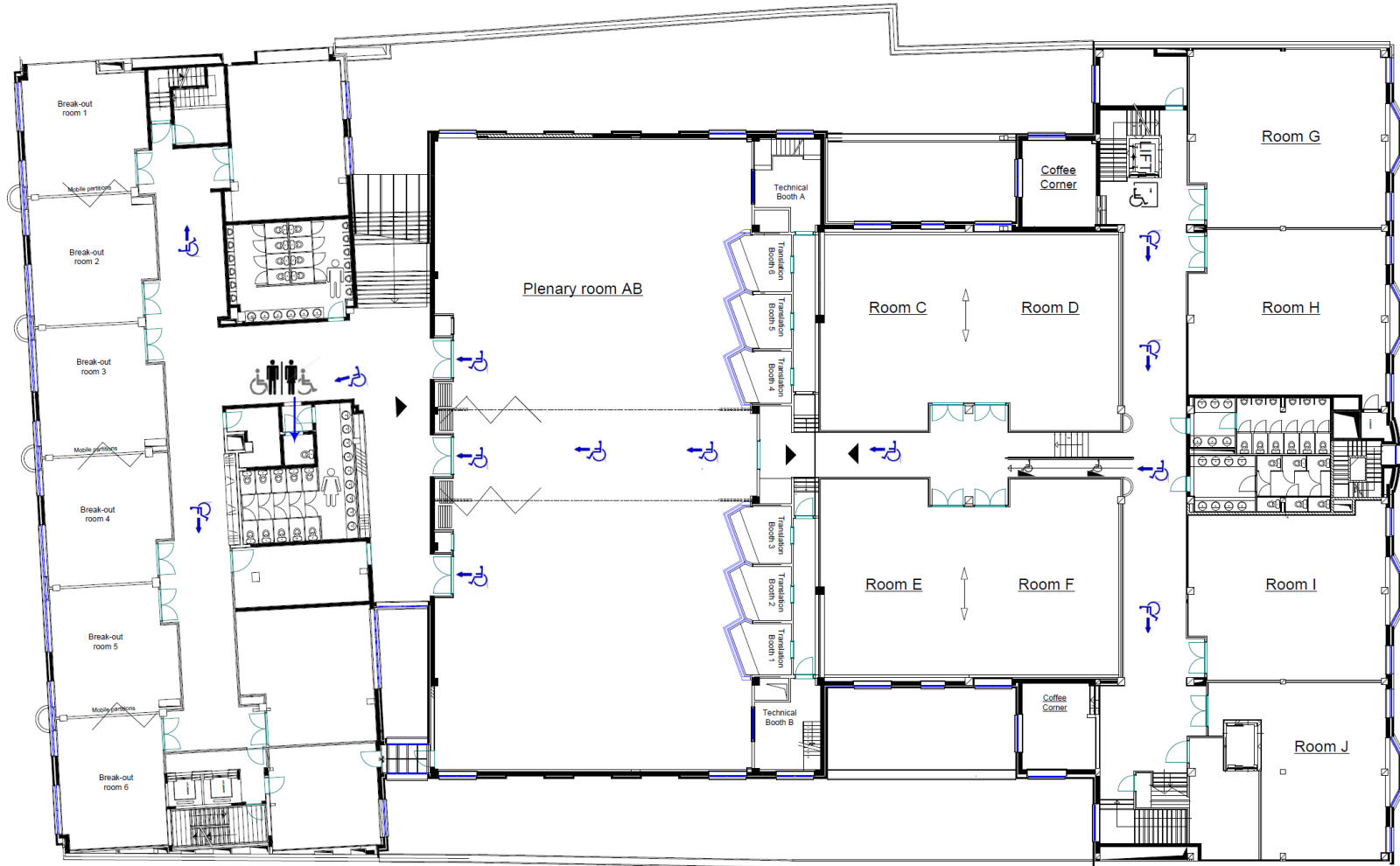
Brussels, May 23, 2012

**Room H, 1st Floor, MCE Conference Centre,
Rue de l'Aqueduc 118, 1050 Brussels, Belgium**

AGENDA

9-9:25	<u>Welcome and objectives of the meeting</u> (D. Taruscio)
9:25	<u>Presentation of the EPIRARE survey</u> (S. Gainotti)
9:45	<u>Quality of the Survey, Quality of the registry data</u> (<i>chapters 4-5.5 of the Working document</i>) (M. Posada)
1030-1100	<u>Coffee break</u>
1100	<u>Ethical Issues, Scope, Governance and Sustainability</u> (<i>chapters 5.6-5.9 of the Working document</i>) (M. Ensini)
1145	<u>Data sets</u> (<i>Annex I of the Working document</i>) (F. Bianchi)
1230	<u>Needs and expectations</u> (<i>chapters 5.10 of the Working document</i>) (L. Vittozzi)
1300-1400	<u>Lunch</u>
1400	<u>General Discussion</u> (L. Vittozzi; EC representative)
1500	<u>The Right to Health of Rare Disease Patients and the Legislative Framework for Rare Disease Registries in EU Policy Documents</u> (D. Townend, A. Brand)
1545	<u>Any Other Business</u> (D. Taruscio)
1600	<u>Conclusions and Next activities</u> (D. Taruscio)
1700	<u>Closure of the Meeting</u>

Full access to the first floor meeting rooms



EURORDIS CONFERENCE