



Agenda

LUNCH DEBATE on DATA PROTECTION:

**POTENTIAL IMPACT OF THE REVISION OF THE CURRENT LEGISLATION on
MEDICAL RESEARCH in the RARE DISEASES FIELD**

26 September 2013 – From 12.30 to 2 pm

Hosted by Marielle Gallo, co-organised by EURORDIS & EPIRARE

“Salon des Députés”, European Parliament

60, rue Wiertz - 1047 Brussels

12.30 – 12.35	<p>Welcome note Marielle Gallo, MEP (EPP, France)</p>
12.35 – 12.45	<p>Projection of the Video “Half of a Score” An EPIRARE project production</p>
12.45 – 1.00	<p>Update of the work in progress in the European Parliament: perspective from the Liberal Group and from the Committee for Industry & Research</p> <ul style="list-style-type: none"> • Baroness Sarah Ludford, MEP (ALDE, UK) • Sean Kelly, MEP (EPP, Ireland) (tbc)
1.00 – 1.15	<p>Presentation of the Opinion of the Legal Affairs Committee (JURI) Marielle Gallo, MEP (EPP, France)</p>
1.15 – 1.30	<p>Practical challenges and the potential impact? Alexander Denoon, Solicitor, Partner Lawford Davies Denoon</p>
1.30 – 1.45	<p>What is at stake for rare diseases patients? John Dart, Deputy General Secretary, EURORDIS Chief Operating Officer of DEBRA International</p>
1.45 – 2.00	<p>Q & A - Take home message</p>