

Rare Diseases Symposium on Cross-Border Care and Patients' Rights in the European Union

Date: 27th February 2025

Time: 8.45 am – 17.00 pm

Venue: European Parliament, salle R3.1

Registration link: <https://eu.eventscloud.com/cbhc-strasbourg>

For technical assistance, please contact crossborder-healthcare-event@cecoforma.com

Agenda

Moderator: Mission maladies rares

8.45 – 9.30	Registration and welcome coffee
9.30 – 10. 10	<p>Welcome addresses</p> <ul style="list-style-type: none"> • <i>by the French Ministry of Labor, Health, Solidarities and Families</i> • <i>by European Commissioner for Health & Food Safety and Donata MERONI, Head of Unit - DG SANTE - European Commission</i> • <i>by Mrs Fabienne KELLER (Deputy, European Parliament)</i> • <i>by Dr Christelle RATIGNIER-CARBONNEIL DG ARS-Grand Est</i> • <i>by HÉLÈNE BERRUÉ-GAILLARD, President of the Board at French National Organization for rare diseases (Alliance maladies rares)</i>
10.10 – 10.35	<p><u>Session 1: Patients' rights in the state of access to healthcare: cooperation in actions</u></p> <p>Access to healthcare in the EU/EEA member states under the Social Security Regulations 883/2004 & 987/2009 and Directive 2011/24/EU</p> <p>The cross-border cooperation areas of the Grand Est: Grande Région (France, Germany, Belgium, Luxembourg), Upper Rhine (France, Germany, Switzerland) and France Wallonia Flanders</p> <p><i>Dr Christelle RATIGNIER-CARBONNEIL (ARS Grand-Est)</i></p> <p>Cooperation for patient rights for cross-border healthcare: general information</p> <p><i>Dr Danièle Rousseau (CNAM) et Solenn BRIERE (Centre national des soins à l'étranger, CNSE)</i></p>
10.35 – 11.25	<p>Patients right in cross border healthcare: examples of concrete cooperation for national diseases policy</p> <p>Chair <i>JP Plançon (Alliance maladies rares, vice-président)</i></p> <p>Panel discussion</p> <ul style="list-style-type: none"> • <i>Dr Christelle RATIGNIER-CARBONNEIL, DG ARS Grand Est</i> • <i>Daniel THEISEN, CEO of ALAN Maladies Rares Luxembourg</i> • <i>Maxime ROUCHON (Regional Social Security)</i> • <i>Pr Jean SIBILIA, dean of the University of Strasbourg's medical faculty</i> <p>Questions and answers</p> <p>Coffee break</p>

11.25 - 11.55

Session 2 : Les droits des patients dans le plan national maladies rares

11.55 – 12.05

Directive 2011/24/EU: Framing patients' rights and entitlements to healthcare in the EU – The impact for rare diseases patients

Pr Hélène DOLLFUS (ERN Eye, SENSGENE, HUS), Dr Jérôme WEINBACH Ministry of Labor, Health, Solidarities and Families (Delegation for European and International Affairs)

12.05 – 12.25

The added value of patients' organisations in shaping rare diseases at, regional, national, European, and international level.

Testimonies: Virginie BROS-FACER – CEO Eurordis and Hélène Berrué-Gaillard (President Alliance Maladies Rares)

12.25 – 13.15

Examples for building ecosystem for national rare diseases plans: Joint action for rare diseases for ERNs integration (JARDIN) - data management between national rare diseases experts centres and ERNs registries.

Chair Dr Alban LERMINE, CEO of the French National Bank for rare diseases (APHP)

Panel discussion

- *Louisa STUWE / Emilie PASSEMARD, Ministry of Health (direction numérique en santé, MoH)*
- *Dr Ana RATH, CEO Orphanet (Inserm)*
- *Pr Hélène DOLLFUS (ERN Eye, SENSGENE, Hôpitaux Universitaires de Strasbourg)*
- *David ASTURIOL Deputy Head of Unit – Digital Health - DG SANTE - European Commission*
- *Hélène BERRUE-GAILLARD (Alliance maladies rares)*
- *Samir HENNI, Hospital Manager (Hôpitaux Universitaires de Strasbourg)*

Questions and answers

13.15 –14h15

Lunch & Coffee

Moderator: Hélène Berrué-Gaillard (AMR)

Session 3: European Reference Networks for Rare Diseases in national health system

14.15 – 14.25

Operating European Reference Networks: national rare diseases policies, organization and cross-linking between countries and Health Care Providers: an 8-year history

Pr Guillaume JONDEAU (APHP, ERN VascERN)

14.25 – 14.35

Opportunities and challenges for the integration of European Reference Networks in national health systems and the role of patients' organizations in Health and Research

Jean-Philippe PLANÇON, vice-Pdt Alliance maladies rares

14.35 – 15.35

JARDIN and ERDERA – collaboration and coordination: National mirror groups, a key to succeed.

Dr Daria JULKOWSKA (Inserm), Dr Anne-Sophie Lapointe (MoH)

Synergies between national strategies for rare diseases and ERNs issues

- Undiagnosed patients: Genomic medicine (*Alexandre MEJAT (AFM-Téléthon) / Ithaca Pr Alain VERLOES (APHP) / SOLVE-RD, Pr Giselle BONNE (Inserm), PFMG*)
- Rare diseases Registries: health and research (ERN Lung, Cystic Fibrosis, FSMR ORKID – ERN Rare Kidney, BNDMR - DOSPERA), *Dr Anne-Sophie JANNOT (APHP)*
- Orphacodes, *Dr Ana RATH (Inserm) and Pr Rima NABBOUT (APHP)*
- Public Private Partnership *Dr Daria JULKOWSKA (ERDERA, Inserm) and WG LSE ERN Pr Hélène DOLLFUS (HUS), Dr Franck MOUTHON (Inserm)*

Questions and answers

Coffee break

16.10 – 16.50

Synthesis and discussion: the ethical view (*Pr Vincent LAUGEL, HUS*)

Session 1: Patients' rights in the state of access to healthcare: cooperation in actions

Session 2: Patients' rights in the French national plan for rare diseases

Session 3: European Reference Networks for Rare Diseases in national health system

16.50 – 17.00

Conclusions of the workshop

Donata MERONI, Head of Unit - DG SANTE - European Commission

Willy PALM, Principal Counselor, World Health Organization