



4th Conference on European Reference Networks

"ERNs in action"

Programme



Organised by the European Commission

Charlemagne Building

Rue de la Loi 170, Brussels

#ERNeu

Fourth ERN Conference "ERNs in action" Brussels 21&22 November 2018

Background:

The evolution of ERN development, as addressed in the 3 previous conferences, could be summarized as:

- 1st Conference: 2014 - Brussels: Exploratory and awareness raising event where the Commission gathered the community of all potential interested actors.
- 2nd Conference: 2015 - Lisbon: Process presentation, criteria and timeline for setting the networks and identification and encouragement of the healthcare community to prepare network proposals.
- 3rd Conference: 2017 - Vilnius: ERNs implementation key moment: launching of the 24 successful network proposals.

4th Conference: Brussels: "ERNs in action"

Since the first conceptualisation of the ERNs system, many challenges have been addressed and actions developed that have made ERNs a reality today.

The ERNs' system is a successful story but is important to consider that the complexity and ambition of the model implies a continuous and proactive analysis of the many challenges that ERNs are facing in the current initial phase and those that will arise in the future.

24 ERNs were launched in March 2017 and now are operational. The ERN model is now a reality and there are a number of dimensions that need to be considered, tackled and managed by all or some of the involved actors (Citizens and patients, National authorities, Members of the ERNs, Healthcare professionals, Hospital Managers and the EU Institutions).

A rich and extremely useful discussion on a number of key issues is ongoing and this conference provides the opportunity to gather again all the actors involved in the ERNs to learn about the experience so far and to find ways and ideas to address the future of the ERNs in the EU.

The objectives of this year's conference will be to:

- Mark that ERNs are entering the next stage of their lifecycle: the deployment phase.
- Present the main clinical and organisational outcomes and success stories of the networks and consider the lessons learned.
- Identify the main challenges, potential improvements and opportunities for the functioning and management of the networks and the way forward for the future of the ERN system.

The 4th ERNs Conference will be a two day event preceded by the meetings of the **ERN Board of Member States** (ERN BoMS), the **ERN Coordinators group** (ERN-CG) and a workshop of **ERNs Hospital Managers**.

Preconference meetings

Tuesday 20 November 2018 in the afternoon

13:30 – 16:30 Meeting of the ERN Board of MS (Centre Borschette)

13:30 – 18:00 Meeting of the ERN-CG (DG SANTE + Centre Borschette)

13:00 – 16:30 Meeting of the ERN Hospital Managers (Hotel Metropole)

19:30 – 21:30 Networking dinner (Metropole Hotel) with the participation of:

- a) the 29 members of the Board of MS
- b) the 24 Coordinators of ERNs
- c) Hospital Managers
- d) Speakers
- e) European Commission representatives (DG SANTE, DG RTD, Commissioner Andriukaitis)

Conference Programme

Wednesday 21 November 2018

- 07:45 – 09:00** Registering of participants, welcoming and networking coffee
- 09:00 – 09:10** Welcome and opening of the conference by *Alexandra Walters*, facilitator of the conference: "*Short review of the structure and presentation of the programme of the Conference*"
- 09:10 – 09:20** Welcome message by *Maggie de Block*, Minister of Health of Belgium
- 09:20 – 09:30** Overall introduction by *Anne Bucher*, Director-General of DG SANTE: "*Past and present of the ERNs: The outcomes until today*"
- 09:35 – 10:50 Plenary: Round table I "State of play of the ERNs: setting up the system"**
Chair: Martin Seychell
- 09:40 – 09:50 State of play of the ERNs. *Andrzej Rys* (Director, DG SANTE, Co-Chair of the ERN Board of MS and of the coordinators group)
- 09:50 – 10:00 Issues addressed and key support developments of the MS to the networks. *Till Voigtländer* (Austrian representative and chair of the ERN Board of Member States)
- 10:00 – 10:10 Key actions developed by the ERN-CG and the networks. *Franz Schaefer* (Co-Chair of the ERN coordinators group & coordinator of ERN ERKNet)
- 10:10 – 10:20 The role and the participation of patients representatives in the Networks. *Yann Le Cam* (Chief Executive Officer EURORDIS)
- 10:20 – 10:30 The role and support of the Hospital Managers: *Eve Parier* (CEO Hôpital Saint Louis, Paris)
- 10:30 – 10:50 Questions & answers session
- 10:50 – 11:20** *Coffee break*

11:25 -12:30 Plenary: Round table II "Tools and resources for deployment"

Chair: Lennart Christiansson (Swedish representative at the ERN Board of Member States)

11:25 – 11:40 The ERN IT platform: How the ERN Clinical Patient Management System (CPMS) works. *Ruth Ladenstein* (coordinator ERN Paedcan) + *Caroline Paquier* (DG SANTE, A4)

11:40 – 11:55 Communication and raising awareness activities on ERNs. *Roser Domenech* (Head of Unit of Communication. DG SANTE 02)

11:55 – 12:10 Financing and supporting the networks. *Stefan Schreck* (Head of Unit DG SANTE C1)

12:10 – 12:30 Q & A

12:30 – 14:00 ***Lunch break & Poster Exhibition***

14:00- 15:00 ***Plenary: Round table III "The EU political and institutional commitment to the ERNs"***

Facilitator: Martin Seychell

14:00 – 14:08 Introduction and Video EU Protect

14:08 – 15:00 **Round table:** Commissioner *Vytenis Andriukaitis* (Health & Food Safety) + Member of the European Parliament *Cristian-Silviu Busoi* (TBC) + Member of the European Parliament *Soledad Cabezon* (TBC) + Video of Member of the European Parliament *Françoise Grossetête*

15:20 – 17:05 ***Parallell sessions 1, 2 & 3***

- **PS 1:** ERN Showcases (Leader: *Franz Schaefer*, chair of the ERN coordinators group & coordinator of ERN ERKNet)
- **PS 2:** Quality assessment, monitoring and evaluation of the networks (Leaders: *Chris Chapple*, *Michelle Battye*, coordinator of ERN eUROGEN & *Enrique Terol*, DG SANTE B3)
- **PS 3:** Epidemiological and Clinical Research and the data challenge (Leaders: *Hélène Dollfus*, coordinator of ERN-EYE + *Iiro Eerola*, DG RTD)

17:20 – 17:40 ***Reporting of parallel sessions to the plenary***

17:40 – 19:30 ***End of the day: Cocktail and Poster exhibition***

Thursday 22 November 2018 (Charlemagne Building)

08:30 Opening doors and welcoming coffee

08:45- 10:15 Plenary: Round table IV. "ERNs' Main challenges for the future"

Chair: Ioana Gligor (Head of Unit DG SANTE B3)

8:55-9:55: **Debate: Speakers:** *Helena Kääriäinen* (Finnish representative at the ERN Board of Member States); *Alberto Pereira* (coordinator ERN ENDO); *Pierre Fenaux* (coordinator ERN EuroBloodNet); *Matt Bolz-Johnson* (EURORDIS ERN and Health Advisor); *Ernst Kuipers* (CEO Erasmus Universitair Medisch Centrum, Rotterdam) tbc

9:55-10:15: Session of Q & A

10:20 – 11:25 Plenary Round table V "The ERN integration in healthcare systems"

Chair: René Wijnen (coordinator ERN ERNICA)

10:25-11:05 **Debate: Speakers:** *Birute Tumiene* (Lithuanian representative at the ERN Board of Member States); *Laura Marin* (Spanish representative at the ERN Board of Member States); *Franz Schaefer* (coordinator ERN ERKNet)

11:05 -11:25 Session Q & A

11:40 – 13:00 *Parallel sessions 4, 5 & 6*

- **PS 4:** Hospital's management and ERNs (Leader: *Eve Parier*: CEO Saint Louis Hospital, Paris)
- **PS 5:** ERNs Sustainability (Leader: Prof. *Kasia Kotulska*, Polish representative at the ERN Board of Member States)
- **PS 6:** Patient-Healthcare professional partnerships in ERNs: sharing successes and challenges (Leaders: *Ines Hernando*, EURORDIS ERN and Healthcare Director, & *Guillaume Jondeau*, coordinator ERN VASCERN)

13:10 – 14:10 *Lunch break & Poster Exhibition*

14:20 – 15:50

Parallel sessions 7 & 8

- **PS 7:** Clinical guidelines and knowledge generation (Leaders: *Maurizio Scarpa*, coordinator ERN MetabERN, *György Pfliegler*, Hungarian representative at the ERN Board of Member States, *Enrique Terol*, DG SANTE B3)
- **PS 8:** New medicines, medical technologies, clinical trials & stakeholders support (Leaders: *Victoria Hedley* – Rare Diseases Joint Action & *Luca Sangiorgi*, coordinator ERN BOND)

16:00 – 16:35

Reporting from parallel sessions 4,5,6,7 & 8 to the plenary

16:40

Closing remarks Andrzej Rys (Director, DG SANTE)

16:50

End of Conference

The event will be transmitted via webstreaming to an extended audience not able to participate in the conference and will also be recorded for dissemination on SANTE webpage.