



The European Study on the Burden and Care of Epilepsy (ESBACE)

Vienna, 30th August 2018

13.00-18.00 (lunch served)

Room: Schubert 1, Messe Wien Congress Centre

The present state of epilepsy care in Europe will be explored:

- What is the prevalence of epilepsy in Europe?
- What are the costs associated with epilepsy in Europe?
- Does stigma and quality of life differ for people with epilepsy across Europe?
- Does seizure management in hospitals differ across European countries?
- What is the status of and resources for epilepsy care in European countries?

The future of care for persons with epilepsy in Europe will be explored:

- What services should be prioritized in order to improve the lives of people with epilepsy?
- How do we measure and monitor improved life in persons with epilepsy?

The EU-funded ESBACE project has worked since 2015 to address these important questions and will for the first time present provisional results at this session during the ECE.

This session should be of interest to professionals in epilepsy care, health care providers as well as people with epilepsy and their families.

The brief presentation of the results will be followed by discussions on how the results can be used to make recommendations for the future care for persons with epilepsy.

Agenda

- 13.00 Welcome, overview and introduction (Jakob Christensen)
- 13.10 Prevalence of epilepsy in Europe (Christine Linehan)
- 13.20 Cost of epilepsy in Europe (Poul Jennum)
- 13.30 Quality of life and stigma in persons with epilepsy (Gus Baker)
- 13.40 Seizure management in hospitals (EuroNASH) (Tony Marson)
- 13.50 Survey of epilepsy care in Europe (Kristina Malmgren)
- 14.00 Group discussions among stakeholders (Jakob Christensen)
 - What services should be prioritized in order to improve the lives of people with epilepsy?
 - How do we measure and monitor improved life in persons with epilepsy?
 - 1. Group – moderator (Christine Linehan & Philip Ryvlin)
 - 2. Group – moderator (Tony Marson & Athanasios Covanis)
 - 3. Group – moderator (Torbjörn Tomson & Martin Brodie)
 - 4. Group – moderator (Jakob Christensen & Politician – TBD)
- 15.00 Coffee break
- 15.30 Continued group discussions
- 16.15 Presentation from the individual group discussions (moderators).
- 17.15 Panel Discussion:
 - The medical perspective (Philip Ryvlin)
 - The patient perspective (Athanasios Covanis)
 - The patient organization perspective (Martin Brodie)
 - The political perspective (TBD)
- 17.45 How can EU/SANTE contribute to improving the life for persons with epilepsy (TBD)
- 18.00 Final remarks (Jakob Christensen)



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Register your interest to attend the session – click [here](#).



ESBACE - European study on the burden and care of epilepsy

The objective and expected results of ESBACE was formulated in the “ANNEX to the COMMISSION DECISION concerning the adoption of the financing decision for 2014 on the 'Preparatory action on 'European study on the burden and care of epilepsy'”

Priorities of the year, objectives pursued and expected results

The strategic objective is to provide the necessary data for allocation of adequate resources for a high-quality epilepsy care equal in all EU countries thus closing the treatment gap, preventing the devastating consequences of epilepsy, reducing unemployment, stigma, and isolation, and securing improved quality of life for people with epilepsy, all in line with the recommendations of the European Parliament’s Written Declaration on Epilepsy.

The specific objective is to build a sustainable system for measuring the burden of epilepsy at EU level in the long term, involving NGOs, stakeholders, and Government organisations, without the need for further financial support from the EU budget. In order to achieve this, the project has to create and demonstrate sufficient value for Member States to motivate long term support by funders at national level, and also to ensure appropriate dissemination of results among budgetary decision makers, and practical support for establishing long term cooperation.

Good practices will be identified and recommendations made for better epilepsy care across Europe.

The results will be used to formulate recommendations to policy makers including methods for follow-up of their implementation and sustainability.