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EpiCARE

# THE STATE OF THE ART OF EPILEPSY CARE IN EUROPE AND OPPORTUNITIES FOR THE FUTURE

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# Europe

- 44 European countries according to UN
- Also 5 transcontinental countries (Russia, Kazakhstan, Azerbaijan, Georgia, and Turkey) and Armenia and Cyprus
- 47 ILAE chapters in 53 countries
- 27 European countries in EU
- EpiCARE centres in EU:  
38 full members and 12 affiliated partners in 26 European countries



# Europe

- A heterogeneous region with regards to economies, provision of healthcare in general, provision of neurologists and provision of epilepsy care



# European efforts to improve epilepsy care

- European epileptologists have been at the forefront working to improve epilepsy care through the ILAE chapters, the close collaboration with IBE and WHO, the European Academy of Neurology and other fora
- Examples of contributions include:
  - The ILAE/IBE/WHO Global Campaign 'Out of the Shadows' launched 1997
  - The European declaration of Epilepsy 1998
  - The WHA Resolution 2015

# NR OF NEUROLOGISTS PER 100 000 POPULATION



Spain 7,76	Slovenia 8,70	Norway 8,55	Greece 9,62	WHO Europe 9	Slovakia 13,84	Germany 13,37	Austria 17,32	Georgia 23,63
Portugal 5,78	Hungary 7,71	Poland 7,55	Luxembourg 8,31	Estonia 9,28	Croatia 9,66	Italy 13,04	Russia 15,66	Latvia 16,35
Kyrgyzstan 3,93	Turkey 5,72	Romania 5,66	Montenegro 7,35	Belgium 8,25	Finland 9,14	Czech Republic 12,27	Bulgaria 11,34	Lithuania 15,63
UK 2,56	Cyprus 3,17	France 4,45	Macedonia 5,52	Serbia 6,76	Denmark 8,09	Moldova 9,00	Armenia 11,86	Ukraine 10,96
Ireland 1,30	Uzbekistan 2,32	Albania 2,60	Sweden 4,33	Israel 5,12	Azerbaijan 5,92	Netherlands 7,81	Kazakhstan 8,94	Switzerland 10,16



Bassetti CLA, Endres M, Sander A, et al.. The European Academy of Neurology Brain Health Strategy: One brain, one life, one approach. Eur J Neurol. 2022;00:1-8.

# The Provision of Epilepsy Care across Europe

## ILAE Special Report 2002

- Survey study, response rate 89% (32/36 European ILAE chapters)
- Wide range in the number of physicians and specialists involved in epilepsy care across Europe
- Differences in the provision of care across countries, with less possibility for patients in the least provided areas to see a specialist

*Malmgren et al Epilepsia 2003*

## EU project (ESBACE) 2019

- Updated survey study, response rate 70% (33/47 European ILAE chapters)
- The number of physicians involved in epilepsy care had increased, most for neurologists.
- The gap between the best-and the least-provided areas with regard to the competence of the providers had diminished.

*Zelano et al Epilepsia open 2019*

# The Provision of Epilepsy Care across Europe

## ILAE Special Report 2002

- Open question about the most important problems in epilepsy care:
- Among the main problem areas:
  - lack of specialists and of specialized epilepsy care
  - insufficient professional education and knowledge about epilepsy

*Malmgren et al Epilepsia 2003*

## EU project (ESBACE) 2019

- Open question about the most important problems in epilepsy care:
- Among the main problem areas:
  - lack of specialists and specialist care
  - lack of comprehensive care
  - insufficient professional education or expertise

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- The European reference networks (ERNs) were created by the EU commission in 2017 as part of a strategy to make European healthcare systems more effective and to improve the care of rare diseases
- EpiCARE is one of 24 ERNs and is focused on **rare and complex epilepsies**
- The main goal is to develop and deliver highly specialized diagnostics and care to improve diagnosis and outcome in individuals with rare and complex epilepsies.
- EpiCARE is coordinated by Prof. Alexis Arzimanoglou at the University Hospitals of Lyon (HCL), France, since 2019. Before that the coordinator was Prof. Helen Cross at GOSH (London, UK).





# EpiCARE

## EpiCARE members



EpiCARE missions revolve around 5 main axes :

- **Sharing medical expertise**

Regular meetings focusing on challenging diagnostic, treatments issues and patients care

- **Research**

Development and contribution to collaborative research projects

- **Sharing of best practices**

Guidelines, publications and protocols

- **Cooperation**

Universities, hospitals, patient associations, scientific societies, EU member states, other ERNs

- **Education and training**

Workshops, webinars, development of practical tools for physicians, families and patients.

## Examples of ongoing clinical activities:

- Regular educational webinars
- Regular video case discussions of complicated patient cases of rare and complex epilepsy
- Fellowship possibilities for physicians
- Exchange programs for epilepsy nurses, biomedical assistants and neuropsychologists
- Transborder care

- [www.epi-care.eu](http://www.epi-care.eu): the website is regularly updated and contains information on current projects and upcoming events
- EpiCARE is present on Twitter (@EpiCARE\_ERN), Facebook (@ERN.EpiCARE) and LinkedIn (ERN EpiCARE - Rare and Complex Epilepsies)
- Any question can be sent to : [info@epi-care.eu](mailto:info@epi-care.eu)
- The patient advocacy group is involved in the majority of EpiCARE activities to represent the patients' voice and improve the impact on the patients' quality of life.
- Any question can be send to : [epag@epi-care.eu](mailto:epag@epi-care.eu)

# Summary

- Europe is a heterogeneous region with varying resources and competence in epilepsy at all levels of healthcare
- There is a lack of epilepsy specialists and comprehensive epilepsy care as well as insufficient professional education and knowledge about epilepsy across Europe
- Educational programs at all health care levels will improve epilepsy care as well as ensure timely referrals of patients to epilepsy centres
- The efforts by EpiCARE have improved and harmonized the care of patients with rare and complex epilepsy in EU countries

# Key issues for future epilepsy care in Europe

- The keys to improved epilepsy care in Europe are through **collaboration, digitalization** and **education**
- This work initiated by EpiCARE will continue and expand within EU but also needs to be adopted in the rest of Europe
- Patients and patient organisations are aware of these coordinated treatment possibilities and demand them
- This together with the political and academic efforts will be a driving force in the work to influence politicians to strengthen epilepsy health care in Europe

Thank you for your attention



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