

Cystic Fibrosis in Serbia: Current State and Future Plans



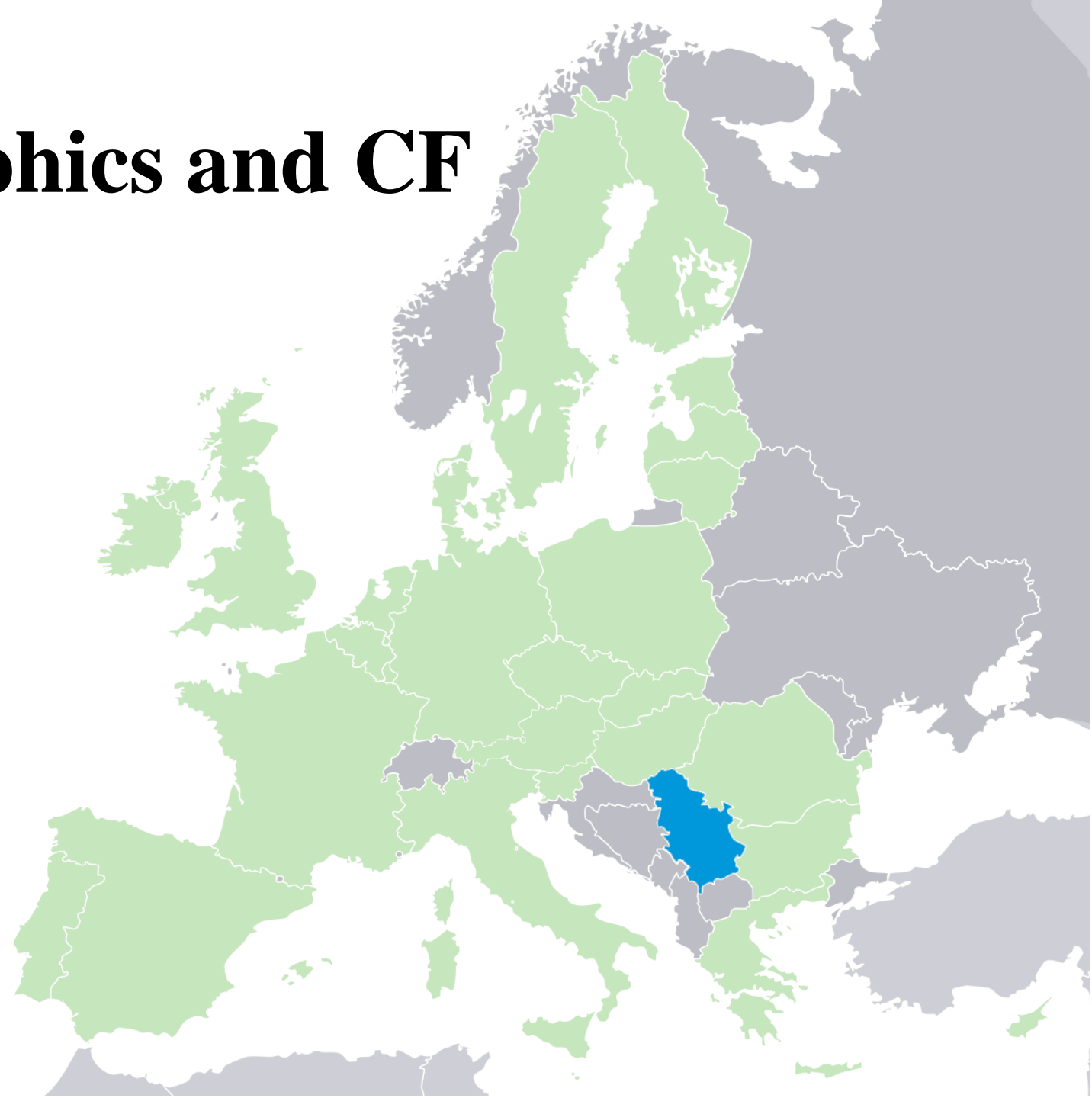
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Serbia - Demographics and CF

- Population: ~ **7.2**
- ~**210 total patients**
 - 70% Pediatric
 - 30% Adult



CF Centre in Serbia

Currently, there is only **1 CF centre** in Serbia fulfilling ECFS Standards of Care criteria – Mother and Child Health Care Institute:

- No adult centre exists

Neonatal screening is performed only regionally (planned to be nationwide by the end of the calendar year 2018)



CF Centre staff

- CF centre is multidisciplinary and staffed with:
 - Pulmonologist
 - Physiotherapist
 - Endocrinologist
 - Surgery
 - Microbiologist
 - Nutritionist
 - Gastroenterologist
 - Psychologist
 - Clinical Nursing
 - Social Worker

*Our CF centre follows **ECFS** guidelines



Challenges and development

Challenges

- Very dependent on the federal funding/support
- Segregation of the patients
 - About 40-60% are chronically colonized (*Pseudomonas aeruginosa*)
- Taking care of adult patient population
- Need to further develop palliative care service and home therapy
- Overcoming transplataion issues (Non developed transplataion center + **Serbia don` t have signed agreement with “Eurotransplant”**)

Development

- Building a new CF center
- Coninuing the lung transplantation program
- Further development of lung function testing (including MBW), cardiopulmonary exercise testing and home i. V. therapy



CF nurse specialist

- There are five experienced pediatric nurses in the service who can deal with many CF patients' issues.
- Still, none of them have accredited training in CF, since there is not such training provided in this country.
- Moreover, they do not have sufficient time, office space, computer/printer and financial support in order to be able to provide a reliable service, as recommended by ECFS Standards of Care.
- Their competencies are good in clinical practice, knowledge in CF and communication with patients and must be improved in other domains.
- All are experienced in performing clinical studies

Core competencies

- Clinical practice
 - Diagnostic and assessment skills
 - Treatment skills
 - Recognizing and monitoring change
 - Facilitating programmes of care
 - Clinical research and audit
- Education
 - Knowledge of CF and associated issues
 - Evidence-based practice
 - Teaching and training: patients, carers, other healthcare professionals
- Communication
 - Patients and carers
 - MDTs
 - Liaison with clinical, social, educational, employment and other lay agencies
- Support and advocacy
 - Social care
 - Advocacy
 - Counselling skills
 - Legal and ethical issues.

Thank you!



Hvala!