ERN: Eastern European dimension
The Patient Perspective

Petia Stratieva
Retina Bulgaria/ERN-EYE EPAG/Bulgarian

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Bulgarian Expert Centres for Rare Diseases

13 Expert Centres – Registered

8 Expert Centres are FULL MEMBERS of EUROPEAN REFERENCE NETWORK

Without the possibility of inclusion of RARE CANCERS

Inclusion of Expert Centres in European Reference Networks DOES NOT influence INCLUSION in the NATIONAL REGISTER

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Rare Diseases Covered by the National Health Insurance Fund & MoH

Beta thalassemia major, Coagulation defects, Idiopathic thrombocytopenic purpura, Certain disorders involving the immune mechanism C1 esterase inhibitor deficiency, Acromegaly and pituitary gigantism, Other hyperfunction of pituitary gland, Hypopituitarism Diabetes insipidus, Cushing syndrome of pituitary origin, Primary adrenocortical insufficiency, Classical phenylketonuria, Disorders of urea cycle metabolism, Glycogen storage disease, Gaucher, Fabry and Niemann–Pick diseases, Mucopolysaharidosis, Wilson–Konovalov disease, Disorders of phosphorus metabolism, Cystic fibrosis, Neuropathic heredofamilial amyloidosis, Myasthenia gravis, Primary muscular disorders , Primary pulmonary hypertension, Pemphigus, Felty syndrome, Juvenile arthritis, Polyarteritis nodosa, Wegener granulomatosis, Dermatopolymyositis, Systemic sclerosis , Bronchopulmonary dysplasia in the perinatal period, Congenital malformations of the circulatory system, Epidermolysis bullosa, Prader–Willi syndrome, Turner syndrome

TOTAL COST FOR TREATMENT PER YEAR – 53 708 439 euro

BULGARIA: Expert Centers status

- Population of Bulgaria: 7 million
- Expert Centers: 15 (8 of them are in 5 ERNs)
- Rare Disease REGULATION: Ordinance (from 2015) on:
  - Rare Disease registration: LIST of Rare Diseases
  - Designation of EXPERT CENTERS
  - Membership of the Expert Centers in ERNs
- An Expert Center is designated upon a Rare Disease registration in the Rare Disease List.
  - 41 Rare Diseases registered in the LIST
  - 39 Rare Diseases applications are pending for registration

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BULGARIA: Rare Disease PATIONTS ACTIONS

On March 26. 2019: ERNs WORKSHOP at the Ministry of Health, organized by the NationalAlliance and the Ministry of Health in collaboration with EURORDIS.

Participants:
=> Deputy Minister of Health (hosting the workshop)
=> Chair of the Rare Disease Commission; Members of the Commission
=> Representatives of Healthcare Providers (Hospitals)
=> Medical Specialists
=> Patients

Facilitator and main key note speaker: Matt Johnson (EURORDIS)

Raising awareness on the ERNs (state of play; challenges; opportunities) among the different stakeholders with the support of the Ministry of Health

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Why Do we NEED ERNs?

- Visibility and Recognition of Rare Disease Experts: We need to know WHO are the EXPERTS and WHERE they are!
- Improved infrastructure supporting RESEARCH (genetic testing, patient registries) and generation of quality DATA
- ERNs main objective is to improve patient ACCESS to quality diagnosis, care and treatment including access to expertise, genetic testing, emerging therapies and rehabilitation services
- Improved Patient Literacy

Vision of Success for ERNs in C&E Europe

- Clear ERN pathways, guidelines and information sharing
- Patient cross-boarder access to highly specialized surgery / interventions and advance therapies provided in a few specialized centres across EU
- Governance for continuous Education and Training of Experts
- Political support to tackle the EU Public Health Need of Rare Disease and ERNs on national level in the Central & Eastern European countries