Endo-ERN short

• 86 Centres in 27 countries
• 16 ePAGs (Denmark, UK, Germany, France, Netherlands, Italy)
• 8 Main Thematic Groups en 5 Work Packages
• Steering Committee for every MTG and WP: Adult and Paediatric Endocrinologist and an ePAG

Advisory Board (no votes)
- ESE & ESPE representatives
- Representatives of other European Endocrine Societies
- National representatives (National Coordinators)

Steering Committee
- 3 chairs per Main Thematic Group and per Work Package (Adult and Paediatric Endocrinologists and ePAG)
- (1 vote per Main Thematic group and per Work Package)

Board (Adult and Paediatric Endocrinologists)
- Chair (coordinator, 1 vote)
- Vice-chair (deputy coordinator, 1 vote)

National Coordinator
- National representative if issues arise linking pin dissemination of expertise

Management board
- (General Assembly, annual meeting)
- Health Care Provider representatives (1 per HCP, 1 vote per HCP)

MTG1: Adrenal
MTG2: Disorders of Calcium & Phosphate Homeostasis
MTG3: Genetic Disorders of Glucose & Insulin Homeostasis
MTG4: Genetic Endocrine Tumour Syndromes
MTG5: Growth & Genetic Obesity Syndromes
MTG6: Pituitary
MTG7: Sex Development & Maturation
MTG8: Thyroid

WP1: Education & Training
WP2: E-Health & ICT
WP3: Research & Science
WP4: Quality of Care & Patient View
WP5: Diagnostics & Laboratory Analysis
• The VSOP (Dutch rare disease National Alliance) is closely engaged with the ministry of Health (VWS), The Federation of University Hospitals (NFU) and patients organisations for rare conditions and they fulfil a fundamental role in the assignment process of centers of expertise and the national plan for rare diseases (NPZZ); next round is expected around the summer.

• Rate of engagement of ePAGs differs enormously; Ranging from established ePAGs and patients who like to learn more on ERNs; some ePAGs never met coordinators and/or chairs or even HCPs from the network

• National Alliance is not fully aware of the work of ERNs; Assumes that every ERNs is organized identically and that creates some misunderstandings and wrong assumptions (e.g. definition of Work Packages)
• Meetings funded on budget provided by ministry of Health; max. 3 meetings in total; after that nothing else will be organised, unless additional funds are provided

• A large meeting with ERN coordinators, ePAGs, University Federation and Ministry of Health will be organized (now postponed due to Covid-19, maybe in June either face 2 face or online)

• Before integrating ERNs in National Networks there still a lot of work to be done: peripheral centers not always are efficiently connected to centers of expertise and also within some ERNs centres of expertise do not always work together effectively and efficiently on a national level, but there are other examples:

• Recent collaboration with the VSOP: Project Connect Extended (Caroline van den Bosch from HEVAS and ePAG Advocate of VASCERN)
VASCERN and the Patient Workgroup

ERN Rare multisystemic vascular diseases (vascern.eu)

VASCERN PATIENT WORKGROUP

VASCERN EUROPEAN PATIENT ADVOCACY GROUP (ePAG)

Caroline van den Bosch – April 16th 2020
Initial situation

- 10 years ago, beginning of collaboration between Hevas and 4 Dutch Centers of expertise on Vascular Anomalies.
- One of the 4 Dutch Centers is Full Member of the VASCA Working group within VASCERN.
- Regular face to face meetings and conference calls.
- Initiating a national network of centres of expertise at national level.
Project Connect Extended

- In 2019, Hevas joined the Pilot Project Connect Extended driven by the Dutch Patient Alliance for Rare and Genetic Diseases (VSOP).
- 26 centres of expertise, 11 patient organisations and 16 rare diseases represented.
- Creation of a common website of centers of expertise.
- Collaboration between centers of expertise, patients and care providers.
- Interaction in the field of care and research.
- Creation of National networks of Centers of Expertise.
Common platform

National Networks of Centers of Expertise and Project Connect Extended with VSOP

Caroline van den Bosch – April 16th 2020
Contribution to patient engagement and improvement of care

- Strong visibility and legitimacy of the participating healthcare centers in a recognized national network.
- Enhance cooperation between patient organisations and centers of expertise but also between the centers themselves.
- Easy access to understandable information for patients and their families.
Success factors and lessons learned

- The Project Connect Extended is a good instrument to enhance a successful collaboration between the participating centers.
- Shared information on patients, treatments and care.
- Collaboration in sensitive topics (research and clinical trials).
- Patient organization at the center of the initiative.
- Possible scaling-up for other disease groupings but limited financial resources.
Thank you!