OUR MISSION

To identify and bring together the best expertise from across Europe to facilitate prevention, diagnosis, management, research and access to the best available care for patients affected by rare inherited metabolic diseases (IMDs).

OUR VISION

Our focus is on establishing a growing and developing network to improve the lives of patients affected by rare inherited metabolic disorders.

OUR AIMS

Pool knowledge and improve information exchange between network members; Improve diagnosis and care in disease areas where expertise is rare; support all Member States to provide highly specialised care to patients affected by IMDs; advance innovation in medical science and health technologies for IMDs; provide cross-border medical training and research on IMDs; support all patient initiatives towards harmonising and improving all aspects of the care chain.

CONTACTS

Get in contact with us via email at coordination@metab.ern-net.eu or by filling the form in the decicated page of our website.

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European Reference Network
for rare or low prevalence complex diseases

Network
Hereditary Metabolic Disorders (MetabERN)

Coordinated by

ASU FC
Azienda sanitaria universitaria Friuli Centrale

Supported by

European Commission

European Reference Network

MetabERN

European Reference Network
for Hereditary Metabolic Disorders

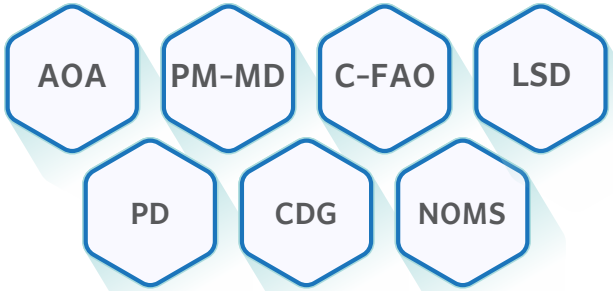
OUR HISTORY

MetabERN is one of the 24 European Reference Networks (ERNs) established by the European Comission in 2017 to facilitate access to the best available care and address the needs across the border for all patients affected by inherited metabolic rare diseases and their families.

The network involves 97 Health Care Providers from the EU and the UK and over 3000 medical professionals and collaborates with over 40 patient associations. It aims at providing EU-wide services focused at improving the quality of life of over 80.000 patients and their families.

OUR STRUCTURE

There are more than 14000 genetic and often lethal IMDs affecting children and adults, all of them of interest for MetabERN. Considering this complexity, IMDs have been divided into the following 7 disorder groups, corresponding to the MetabERN subnetworks:



AOA: Amino and organic acids-related disorders
PM-MD: Disorder of pyruvate metabolism, Krebs cycle defects, mitochondrial oxidative phosphorylation disorders, disorders of thiamine transport and metabolism
C-FAO: Carbohydrate, fatty acid oxidation and ketone bodies disorders
LSD: Lysosomal storage disorders
PD: Peroxisomal disorders
CDG: Congenital disorders of glycosylation and disorders of intracellular trafficking
NOMS: Disorders of Neuromodulators and Other Small Molecules

OUR TOOLS

- The Unified European Registry for Inherited Metabolic Disorders (U-IMD), the first observational, non-interventional patient registry that encompasses all known IMDs (u-imd.org)
- The Clinical Patient Management System (CPMS), an IT platform for clinical consultations facilitating collaboration within our network of experts across Europe
- The online emergency protocol tool (www.emergencyprotocol.net), able to automatically generate personalized emergency letters for families and patients with different IMDs

OUR ACTIVITIES

- Facilitate the development of clinical practice guidelines and clinical decision support tools for the management and treatment of IMDs.
- Design training and educational activities addressed to healthcare professionals, patients and caregivers.
- Fostering of research in the field of IMDs
- Support of patient empowerment and improvement of patient experience.