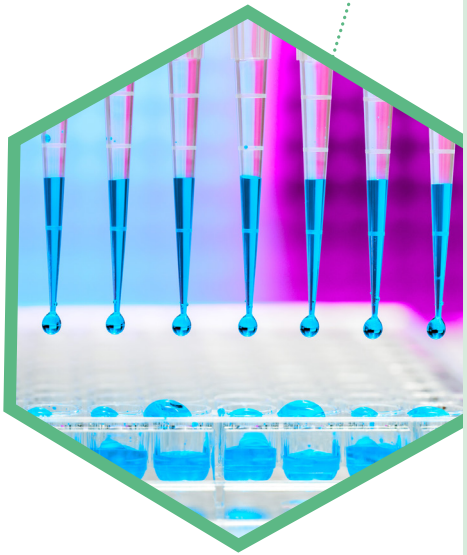
# ERN on hereditary metabolic disorders (MetabERN)

*Rare inherited metabolic diseases (IMDs), of which there are more than 1400, are individually rare but collectively frequent. Many metabolic diseases have severe - sometimes life-threatening - implications for patients. These conditions include disorders of all organs, can affect people of any age, and require multidisciplinary collaboration between a range of professionals.*



Early diagnosis can improve outcomes, but only five percent of known IMDs are currently included in newborn screening programmes in Europe and there is a need for national programmes to be harmonised. Many IMDs lack knowledge about their natural history and the efficacy and safety of therapies, while long-term follow-up is incomplete.

MetabERN seeks to improve the lives of people affected by this highly heterogenous group of diseases by dividing them into seven main categories. The network represents the most comprehensive, pan-metabolic, pan-European, patient-orientated network, aiming to transform how care is provided to patients with IMDs in Europe.

MetabERN uses the Clinical Patient Management System (CPMS) as a referral platform for clinical decision-making processes and for fostering translational research programmes across IMDs. With its fully operational unified European registry for IMDs (U-IMD), developed with a grant from the EU Consumers, Health, Agriculture and Food Executive Agency (CHAFEA), MetabERN effectively generates patient data for research purposes. This allows a detailed assessment of the natural history of IMDs, as well as the investigation of further research questions, including prospective analysis of preventive and therapeutic interventions in patients with IMDs. Moreover, U-IMD is the first observational, non-interventional patient registry to encompass all 1400+ IMDs.

**NETWORK COORDINATOR**

**Professor Maurizio Scarpa**
*Udine University Hospital, Udine, Italy*