Collaborating Partners

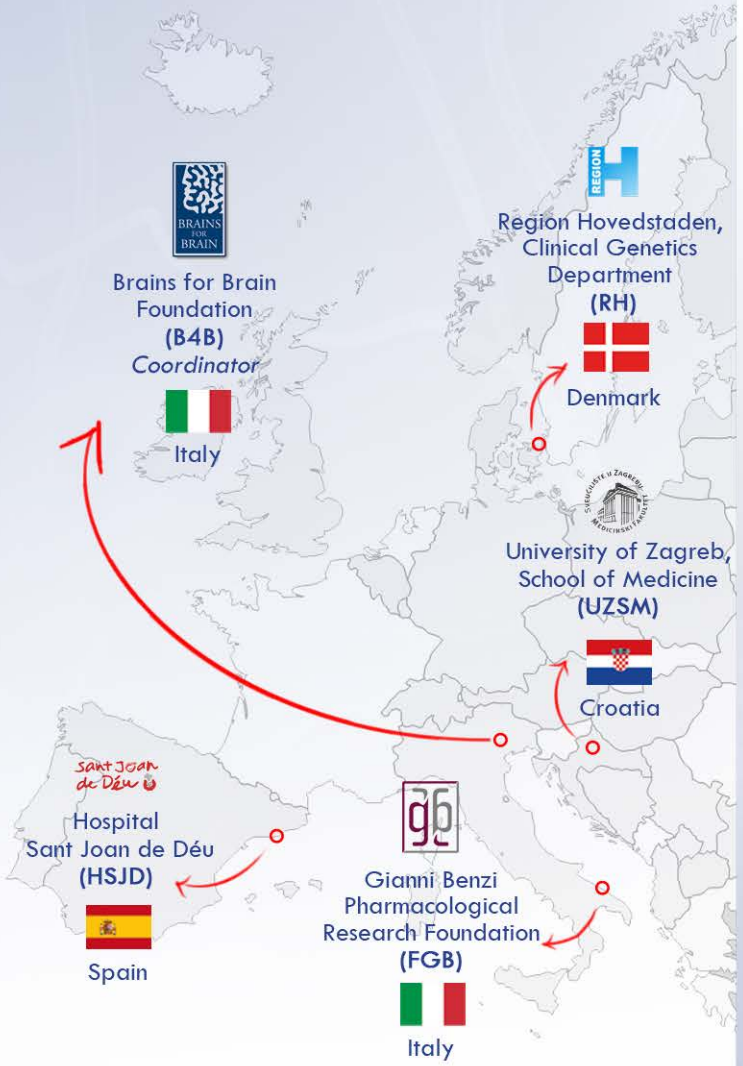
Shaare Zedek Medical Center (Israel)
Children Memorial Institute (Poland)
Hospital de Clinicas (Brazil)
Department of Pediatrics and Amsterdam Lysosome Center (The Netherlands)
Kings College London (United Kingdom)
University of Oxford (United Kingdom)
Institut fuer Physiologische Chemie and European Study Group For Lysosomal Diseases (Germany)
Fundació Sant Joan de Déu (Spain)
University of British Columbia (Canada)
University of Cambridge Medical School (United Kingdom)
Niemann-Pick Disease Group (United Kingdom)
St Mary's Hospital (United Kingdom)
European Brain Council (Belgium)
The Society for Mucopolysaccharide Diseases (United Kingdom)
Gauchers Association Ltd (United Kingdom)

Other projects focused on iNMDs

DG-SANCO PROJECTS:
E-HOD (VUmc, the Netherlands)
E-IMD (Universitätsklinikum Heidelberg, Germany)
NPDR (UHB, United Kingdom)

CORDIS PROJECTS:
AC FOR PKU TREATMENT (Aarhus Universitet, Denmark)
AIPGENE (FIMA, Spain)
DEM-CHILD (UKE, Germany)
IEMTX (Telethon, Italy)
JIMPYSPEC (ULP, France)
LEUKOTREAT (UdA, France)
MOCOMODELS (Ernst-Moritz-Arndt-Universität Greifswald, Germany)
NO-BRAINER (WIS, Israel)
STORAGE PROTEOMICS (UKB, Germany)
TIRCON (LMU, Germany)
TREPAPHEN (Aston University, United Kingdom)

InNerMeD Partners



FOR FURTHER INFORMATION:
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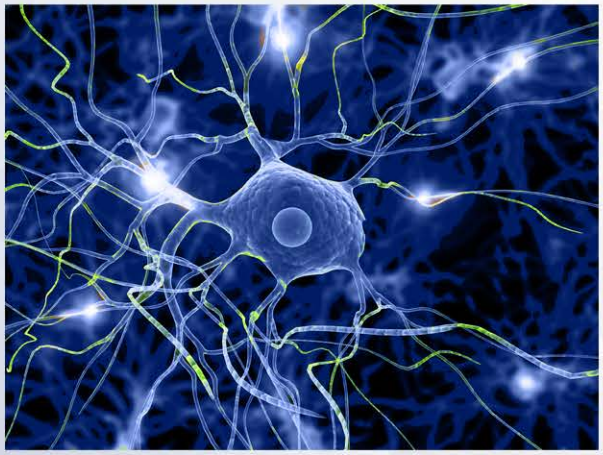
InNerMeD
Inherited NeuroMetabolic Diseases Information NETWORK

The first European Network on Inherited NeuroMetabolic Diseases



Co-funded by the Health Programme of the European Union

This leaflet arises from the project InNerMeD-I-Network, which has received funding from the European Union, in the framework of the Health Programme

Why InNerMeD?

Inherited NeuroMetabolic Diseases (iNMDs) represent an important group of Rare Diseases constituted by genetic metabolic disorders showing clinical neurologic/cognitive symptoms at any time of the disease progression.

Unfortunately, data on iNMDs are today not only few but also very badly disseminated outside the restricted arena of the experts; at the same time, there is a lack of awareness about these conditions that can delay the diagnosis and the start of treatment, with consequent tragic results.

In fact, the advancement of knowledge on biochemical and molecular basis of the diseases do have important effect on the development of innovative therapies which may modify the natural history of the disease and slow the neurodegeneration process. In addition, the pharmacogenetic and genetic advancements can make possible pre-symptomatic and, in many cases, prenatal diagnosis.

Increasing awareness is therefore the first crucial step in fighting these conditions.

What is InNerMeD?

InNerMeD is a European project, started on April 2013, with the aim to create a multimedial Network of information targeted on research, diagnosis and treatment of iNMDs and based on the collection and exchange of validated information among scientific communities, health professionals, patients, patient associations and all relevant stakeholders.

The Network will increase the current knowledge on iNMDs, speed up the timely and precise identification of patients, who may benefit of the available (experimental and marketed) treatments and also favour biomedical research.

InNerMeD Objective

The general objective of InNerMeD is to create a critical mass of multi specialist knowledge to be disseminated in order to:

- increase awareness on these rare conditions among physicians, patients and general stakeholders to anticipate diagnosis and, when available, supply an adequate therapy;
- straighten research capacities and foster technological innovation in favour of the population affected by iNMDs;
- provide practical support for sharing experiences at global levels on iNMDs;
- disseminate knowledge on clinical and experimental approaches for diagnosis and treatment of iNMDs, to make patients and families empowered and aware as real actors for the correct management of the disease.

Expected Outcomes

The Network will contribute to reduce the gap affecting iNMDs in different ways:

- providing a critical mass of competences, instead of a dispersed expertise;
- providing validated customised information at all levels about iNMDs;
- stimulating innovative research projects to enforce European leadership on iNMDs;
- fostering the identification of group of patients to be included in biomedical research (registries and clinical trials);
- translating scientific breakthroughs into clinical practice;
- generating social benefit to the aim of establishing a standard of care for patients with iNMDs across Europe.

InNerMeD Strategy

WP1 - Coordination of the project

WP Leader
Brains for Brain Foundation

WP2 - Dissemination of the project: Efficient communication with stakeholders and awareness raising on the project

WP Leader
Brains for Brain Foundation

WP3 - Evaluation of the project: Actions to verify project implementation and fulfillment of objectives

WP Leader
Region Hovedstaden, Clinical Genetics Department

WP4 - Networking: Establishment of an enlarged network of experts and organisations competent on iNMDs field

WP Leader
University of Zagreb, School of Medicine

WP5 - IT platform: Creation of a web-based platform to collect, share and disseminate validated information on therapies, diagnosis and research

WP Leader
Gianni Benzi Pharmacological Research Foundation

WP6 - Production of scientific documents to be disseminated by the network: Scientific validation of collected information for documents production

WP Leader
Hospital Sant Joan de Déu

WP7 - Activities favouring biomedical research: Production of recommendations based on best practices and most recent advancements in iNMDs diagnosis and treatment

WP Leader
Gianni Benzi Pharmacological Research Foundation