



Press Release #1

InNerMeD-I-Network

Inherited NeuroMetabolic Disease Information Network

Kick-off Meeting

Luxembourg, May 21st 2013. In the Jean Monet Building of the European Commission in Luxembourg, a new project co-founded by the European Commission, Executive Agency for Health and Consumers (EAHC), was officially kicked off on May 21st 2013. The InNerMeD-I-Network project, which will last 30 months, is coordinated by the Brains for Brain Foundation (B4B, Italy) and counts other five partners, from five different European countries, including a non-profit scientific research organisation and four clinical/academic institutions.

The project aims to create a Network of information about the Inherited Neurometabolic diseases (iNMDs), based on the collection and exchange of validated information among scientific communities, health professionals, patients, patient associations, public health authorities, pharmaceutical companies and other interested parties.

iNMDs are an important group of Rare Diseases constituted by genetic disorders of metabolism that show clinical neurologic/cognitive symptoms at any time of the disease progression. "Today, there is a general lack of awareness of these conditions but, despite this, in some cases, treatments exist which, if promptly used in new-borns or young children, can slow the neurodegeneration process and increase the life expectancies" explained the coordinator Dr. Maurizio Scarpa, who opened the event giving an overview of the project. "Unfortunately, data on iNMDs, including diagnosis, treatment options, epidemiology, biomedical and pharmacological research, are scarce as well as poorly disseminated outside the restricted group of experts that are also inadequately connected" he added, concluding that "increasing awareness is the first crucial step in fighting these conditions". The increase of awareness about the iNMDs is exactly the main aim of the project that will be primary achieved through the set-up of a Network involving at first the project's partners themselves and then, other people and organisations having both interests and competences in the iNMDs field, as explained by Dr. Christine Lampe, from the University of Mainz (UMC-M, Germany).



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Dr. Viviana Giannuzzi, from the Gianni Benzi Pharmacological Research Foundation (FGB, Italy), showed how the interconnection among the nodes of this Network and the dissemination of the Network products will be performed through the development of a publicly available platform assuring user-friendly access and easy exchange of information. In this context, the activity of dissemination of the project's results and deliverables will play a very important role for the success of the InNerMeD project. All the communication activities including the design of a graphic identity, the set-up and maintenance of a dedicated website, the project related publications and the dissemination of informative materials were presented in detail by Dr. Donato Bonifazi from FGB. Prof. Adriana Ceci, President of the FGB, stressed the need to use a simple language suitable for the different user categories, including patients and families, to whom the project is targeted. Dr. Angeles Garcia Cazorla, from the Hospital Sant Joan de Déu (HSJD, Spain), underlined the importance to assess the scientific evidence in the collected and integrated information and to assemble it scientifically through document summarising the current knowledge and the most recent advances in the field of iNMDs; she also showed how the project planned to satisfy this issue.

As regards the activities favouring biomedical research on iNMDs, which is another important aim of the project, Prof. Adriana Ceci highlighted the difficulty in performing studies in this field. Being iNMDs paediatric and rare diseases, the recruiting of children in biomedical research and clinical trials is limited by the geographic dispersion, the reduced number of patients and by many economic, methodological and ethical issues. In this context “the InNerMeD project aims to reduce existing gap favouring and increasing the recruitment of children and by mean of non-conventional way to obtain evidences”, explain Prof. Ceci. She also proposed to involve the InNerMeD project into the revision process of the EU Directive 2001/20/EC, regulating the clinical trials in Europe, and in the European network of paediatric research (EnPrEMA).



The meeting represented an important occasion to discuss the entire outline of the InNerMeD project and to analyse in details the individual workpackages. Administrative, technical and financial issues were also discussed thanks to the talks of Dr. Fedele Bonifazi, from FGB, and of Hristina Mileva, Project Officer at the European Commission.



All the official partners of the project were present, together with the representatives of some of the collaborating partners: King's College London, International Niemann Pick Alliance, The Batten Disease International Alliance and the MPS (Mucopolysaccharidoses) Association. The meeting gave all participants a better understanding of the tasks and the goals of InNerMeD-I-Network, which seemed to be an ambitious project targeting a very demanding and socially important issue.

InNerMeD-I-Network Partners



BRAINS FOR BRAIN FOUNDATION (B4B) - ITALY



GIANNI BENZI PHARMACOLOGICAL RESEARCH FOUNDATION (FGB) - ITALY



HOSPITAL SANT JOAN DE DÉU (HSJD) - SPAIN



REGION HOVEDSTADEN, CLINICAL GENETICS DEPARTMENT (RH) - DENMARK



JOHANNES GUTENBERG UNIVERSITY OF MAINZ, (UMC-M) - GERMANY



UNIVERSITY OF ZAGREB, SCHOOL OF MEDICINE (UZSM) - CROATIA

Press enquiries: Francesca D'Avanzo

E-mail: info@innermed.eu



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