Who are we? How do we collaborate?

DESIRE consists of 25 partners from 11 countries, with more than 250 researchers and 19 clinical centres. The partners co-operate in the various WPs as in the diagram below.



P1 - UNIVERSITA DEGLI STUDI DI FIRENZE (co-ordinator)

- P2 FONDAZIONE IRCCS ISTITUTO NEUROLOGICO CARLO BESTA
- P3 INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE (INSERM)
- P4 UNIVERSITAETSKLINIKUM ERLANGEN
- P5 UNIVERSITA DEGLI STUDI DI VERONA
- P6 CENTRE NATIONAL DE LA RECHERCHE SCIENTIFIQUE
- P7 ISTITUTO ITALIANO DI TECNOLOGIA
- P8 AGENCIA ESTATAL CONSEJO SUPERIOR DE INVESTIGACIONES CIEN-TIFICAS
- P9 KING'S COLLEGE LONDON
- P10 CHARITE UNIVERSITAETSMEDIZIN BERLIN
- P11 KLINIKUM DER UNIVERSITAET ZU KOELN
- P12 UNIVERSITY COLLEGE LONDON
- **P13 THE UNIVERSITY OF LIVERPOOL**
- P14 UNIVERSITE LIBRE DE BRUXELLES
- P15 CHRISTIAN-ALBRECHTS-UNIVERSITAET ZU KIEL
- P16 BAKER IDI HEART AND DIABETES INSTITUTE HOLDINGS LIMITED
- **P17 UNIVERSITA TA MALTA**
- P18 DI.V.A.L. TOSCANA SRL
- P19 MICROMED S.P.A.
- P20 VARIONOSTIC GMBH
- P21 CEGAT GMBH
- **P22 AMARNA THERAPEUTICS BV**
- P23 CF CONSULTING FINANZIAMENTI UNIONE EUROPEA SRL
- P24 UNIVERSITA CATTOLICA DEL SACRO CUORE
- **P25 OSPEDALE PEDIATRICO BAMBINO GESU**

Do you wish to learn more about DESIRE?



For more information go to our website

www.epilepsydesireproject.eu

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Strategies for Innovative Research to improve diagnosis, prevention and treatment in children with difficult to treat Epilepsy

www.epilepsydesireproject.eu

What is **DESIRE**?

DESIRE is an FP7 funded project (Grant Agreement no: 602531), involving 25 partners in 11 countries. It is coordinated by Prof. Renzo Guerrini, Dipartimento di Neuroscienze, Universita degli Studi di Firenze, Italy.

DESIRE will focus on epileptogenic developmental disorders (EDD), i.e. early onset epilepsies whose origin is closely related to developmental brain processes. A major cause of EDD are malformations of cortical development (MCD), either macroscopic or subtle. EDD are often manifested as epileptic encephalopathies (EE), i.e. conditions in which epileptic activity itself may contribute to severe cognitive and behavioral impairments. EDD are the most frequent drugresistant pediatric epilepsies carrying a lifelong perspective of disability and reduced quality of life. Although EDD collectively represent a major medical and socio-economic burden, their molecular diagnosis, pathogenic mechanisms (PM) and rationale treatment are poorly

DESIRE will address this lack of understanding in various ways, in eight workpackages.

How is DESIRE organized?

As with all EU projects, DESIRE is organized into a series of Work Packages (WPs) which focus on different aspects of the research. In DESIRE there are eight WPs, are closely interrelated as shown in the workplan below.



WP1 - Identifying genetic causes and pathophysiological mechanisms of epileptogenic brain malformations

WP2 - Identifying genetic causes and pathophysiological mechanisms of epileptic encephalopathies

WP3 - Validating High Frequency Oscillations (HFOs) as a biomarker of the seizure onset zone

WP4 - Improving Diagnostic Tools and Protocols in Cortical Dysplasia

WP5 - Improving epilepsy treatment in children with Focal Cortical Dysplasias (FCD) Type II as classified by the International League Against Epilepsy (ILAE)

WP6 - Innovative strategies for treatment and prevention of Epileptogenic Developmental Disorders (EDD) related epilepsy and of its consequences

WP7 - Dissemination and Exploitation

What are the objectives of DESIRE?

As explained in the diagram below, the specific objectives of DESIRE are to advance the state of the art with respect to:

- 1. the genetic and epigenetic causes and PM of EDD, particularly epileptogenic MCD, to elucidate molecular networks and disrupted protein complexes and search for common bases for these apparently heterogeneous disorders.
- 2. the diagnostic tools (biomarkers) and protocols through the study of a unique and wellcharacterized cohort of children to provide standardized diagnosis for patient stratification and research across Europe.
- treatment of EDD using randomized, multidisciplinary clinical protocols and testing preclinical strategies in experimental models to also address novel preventative strategies.



The workplan thus spans from clinical observation, to whole exome studies, cellular and animal models and basic research, identification of biomarkers and improvement of diagnostic methods, and back to the clinical trials and assessment of innovative, targeted treatment strategies.

The consortium partners have an outstanding track record in genetics, basic neurophysiology, neuropathology and clinical research. Specialized expertise will be made available by the small and medium enterprises (SMEs) involved to develop novel diagnostic tools for tailored treatment approaches.