



## Rare disease and Pregnancy: the EDERA project .<sup>†</sup>


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Rare diseases (RDs) are an important public health problem and an ongoing challenge for the medical community and health policy. Because of the problems associated with access to care and information, people with RDs are very vulnerable at psychological/social/cultural level. These difficulties are more emphasized for pregnant women or for women that would undertake a pregnancy but that often decide to abandon the maternity project. In this context, stands the project EDERA (Early DEtection of Rare diseAses) in response to a regional call promoted by the Agenzia Regionale per la Salute ed il Sociale (AReSS Puglia) that sees the collaboration between the group of Databases and Information Systems of the Department of Engineering for Innovation of the University of Salento and 4 associations (HHT Onlus, CIDP Italia Onlus, APMAR Onlus and ANACC Onlus).

The overall objective of the project is the knowledge development in the field of maternal, fetal and child health monitoring for the prevention, surveillance and early detection of RDs during and after pregnancy in order to discover potential correlations and to monitor appropriate indicators that may influence children neurocognitive development. Specifically, the project aims at creating a digital system for monitoring maternal, fetal and child health by means of innovative techniques for data collection that exploit smartphones as a complementary, if not alternative, way to common methods for collecting data. Patients will be able to easily provide data related to lifestyle (nutrition, physical activity, drugs, etc.), pregnancy (symptoms, treatments, moods, etc.), delivery (type, complications, etc.) and childhood (weight, motor function, stimulus response, etc.). Data will be shared in real time respecting the rules on privacy and treatment of sensitive data, through accurate access management techniques.

The approval of the project is a good starting result and shows the high interest of the medical community and health policy on these issues. The system will be tested and validated on the field in collaboration with physicians, associations and patients considering a comprehensive approach that takes into account the heterogeneity of genotypes, phenotypes and lifestyles of patients. The network will include not only the proposing 4 associations but also other external partners interested in the initiative that will be involved in the awareness campaign, with the participation of different departments of hospitals throughout the Puglia region with the active participation of medical specialists (gynecologists, obstetricians, pediatricists, neurologists, neurosurgeons, etc.) that will contribute to present the initiative to the patients.

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