



Extension a European Network for Orphan Cardiovascular Diseases **Rare diseases**

Rare cardiovascular diseases are becoming a significant burden for patients, physicians, and the health care system. A “rare” disease is a disease seen so rarely that its appropriate diagnosis and treatment require specific, complex endeavors in the hands of appropriately trained and experienced physicians. Rare diseases are estimated to affect 30 million European Union (EU) citizens. These diseases are chronic, progressive, and often life-threatening. Rare cardiovascular diseases are often disabling – the quality of life of the patients is frequently compromised by the lack or loss of autonomy.

Design

The project implemented from 2013 in John Paul II Hospital in Krakow is co-financed under the by the Malopolska Regional Operational Programme 2007–2013, Priority 8, Interregional cooperation, Action 8.2. Strengthening the position of Malopolska in the European cooperation network.

Project partners

The first official partners have centers in Riga, Pauls Stradins Clinical University Hospital and in Kaunas, Lithuanian University of Health Sciences. Then the project was joined by Deutsches Herzzentrum in Berlin, Germany, San Raffaele University Hospital, Milan, Italy, Specialist Hospital Edward Szczeklik in Tarnow, Dr. Titus Chałubiński District Hospital in Zakopane, County Hospital in Chrzanów, University Children's Hospital in Krakow-Prokocim Jagiellonian University Medical College / Jagiellonian University, National Health Fund, Malopolska Division.

The main objectives of the project

- Improve the competitiveness of Malopolska as a European center of advanced diagnosis and treatment of orphan diseases of the heart;
- Undertake joint initiatives in the area of Central and Eastern Europe;
- Improving the qualifications of participants in the projects;
- Equal opportunities in access to diagnosis and treatment of orphan diseases cardiac patients from Galicia and other European centers through education of medical personnel and create a network of consultation;
- The creation and coordination of a regional network of cooperation with cardiac centers in Galicia and Europe;
- Creating a "model of traffic management of patients with rare diseases of the circulatory system" based on the known project solutions abroad, ready to deploy on Polish soil by stakeholders from the Malopolska region;
- Creation of information system of registries for rare diseases of the circulatory system;
- Develop a curriculum for rare diseases of the circulatory system for the students of medical

- Using the experience of centers partner in the diagnosis and treatment of patients with rare diseases of the circulatory system and developing appropriate algorithms as well as the exchange of experience, knowledge, know-how and good practice;
- Gain clinical experience in the treatment of patients with rare heart disease at the time of placement in specialized centers abroad;
- Conducting practical, highly specialized clinical internships in our center for training in the diagnosis and therapy of rare diseases of the heart;
- The creation of registries for orphan diseases cardiology;
- Dissemination of knowledge on orphan diseases cardiac and results of the project;
- Participation in the development of European standards in relation to key issues related to the creation of a new Europe.

Contact

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- **Lietuvos sveikatos mokslų universitetas, Kaunas** – prof. Remigijus Zaliunas
- **Ospedale San Raffaele** – prof. Ottavio Alfieri
- **Das Deutsche Herzzentrum Berlin** – prof. Roland Hetzer
- **The Edward Szczeklik Specialist Hospital** – Marcin Kuta, MD
- **Municipal Hospital in Chrzanow** – Krzysztof Kłos, MD
- **University Children's Hospital of Cracow** – Maciej Kowalczyk, MD
- **The Tytus Chałubiński Hospital in Zakopane** – Regina Tokarz, MD