



## **Extension a European Network for Orphan Cardiovascular Diseases**

### **Results of the project**

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.

Centre for Rare Cardiovascular Diseases at the John Paul II Hospital stemmed from the growing experience that staff of the John Paul II Hospital in Krakow and the Institute of Cardiology, Jagiellonian University Medical College had gained throughout the years. The Centre was formally established in 2011, as a result of our successful

application for the European Union Project "Establishing a European Network for Orphan Cardiovascular Diseases", cofunded by the Małopolska Regional Operational Programme 2007–2013.

The aims of the CRCD are consistent with the identified needs for centers of excellence in rare cardiovascular diseases (RCDs) as indicated by the European Union Commission on Rare Diseases These have included as follows:

- providing efficient diagnostic and therapeutic pathways for RCD patients in the Krakow (Małopolska) region and (as needed) from other Polish regions;
- development of national and international collaboration network in RCDs;
- establishing a database of RCDs;
- knowledge dissemination, targeting both physicians and patients/families;
- psychological and social support to patients and families.

From 2006 to 2015, the CRCD has been instrumental in providing diagnostic path and making key therapeutic decisions for hundreds patients with RCDs. This was possible due to strict cooperation of the staff of the CRCD with national and international experts in various medical disciplines. Patients with RCDs have been discussed thoroughly during quarterly videoconsultation meetings with experts. Physicians from the CRCD have been training their skills in RCDs in renowned European Centres. In addition CRCD has played an important role in the dissemination of knowledge on RCDs through symposia and conferences, RCD registries, textbook, RCD website ([www.crcd.eu](http://www.crcd.eu)), and the Journal of Rare Cardiovascular Diseases.

CRCD in cooperation with the Faculty of Medicine of the Jagiellonian University Medical College has developed a "Curriculum in the field of rare diseases". In order to facilitate transfer of patients from referring centers to the Center for Rare Diseases "Model of Referring Patients Suffering from Rare Diseases" developed within the project.

In order to facilitate recognition of RCDs, and to group the expertise in the main fields of RCDs the RCD Classification Working Group has recently published in the Journal for Rare Cardiovascular Diseases their proposal for the first ever "Classification of Rare Cardiovascular Diseases"

### ***The Curriculum in the Field of Rare Diseases for Medical Students***

The document presents an overview of European Union recommendations on how to introduce education systems on rare diseases in the associated countries, then presents the proposed plan of organization of classes for medical students. The schedule is complemented by collection of comprehensive data on specific issues that should be provided by a university teacher as well as the description of the methodology of teaching. The program includes also examples of case histories of patients.

## **The registration system for rare diseases of the circulatory system**

This is a web application that allows physicians from Malopolska and from other regions of the country to transfer patients data to the Centre for Rare Cardiovascular Diseases. When you sign up to the system the patient should be classified in a group of diseases due to classification of the Centre for Rare Cardiovascular Diseases, type the patient's data and basic information on the patient's symptoms and results of additional tests. These data will be submitted to the Coordinator of the group of diseases, which will contact a referring physician.

## **Model of Referring Patients Suffering from Rare Diseases**

Center for Rare Cardiovascular Diseases along with the Malopolska Branch of the National Health Fund have developed a Model of Referring Patients Suffering from Rare Diseases which aims to improve the system of consultation and referral of patients from referring centers (peripheral units) to the Center of Cardiovascular Rare Diseases.

## **Video teleconsultations**

Based on previous experience in collaboration with pediatric cardiologists and cardiac surgeons from Institute of Pediatrics of the Jagiellonian University Medical College in Krakow, with additional financial and logistic support from European Union projects "Establishing a European Network for Orphan Cardiovascular Diseases" and "Development of the European Network in Orphan Cardiovascular Diseases", the Centre initiated in 2011, organizing quarterly consultation meetings, during which the most difficulty RCD cases are discussed. For this initiative, a number of cooperation links with a wide range of specialists from Poland and Europe has been developed. There has been 22 meetings convened up to date. With the means of internet-based TeleDICOM platform, a simultaneous participation in these meetings of experts from Poland and abroad has become possible. The meetings are held in specially equipped teleconference room in the John Paul II Hospital. Since 2013, doctors from local hospitals in Malopolska region have been given the opportunity to consult their RCD patients directly with experts from the Centre on live.

## **Website**

The CRCD website ([www.crcd.eu](http://www.crcd.eu)) established in 2011 plays an important role in the achievement of the key goal of the CRCD – dissemination of knowledge.

The majority of clinical cases discussed during the quarterly international live videoconferences in 2011-2013 and CRCD Workshops on ESC conferences in Paris in 2011 and Munich in 2012 are available on the website. RCD patient presentations include a short case description, results of diagnostic procedures, and literature review. All these reports feature expert opinions and conclusions concerning the agreed diagnostic and treatment approach. The news section provides important and up-to-date information about the events and activities of the center. The "easy search" feature

based on the new classification of RCDs is a quick way to find relevant information about RCDs.

The CRCDD website is linked to the website of the Journal of Rare Cardiovascular Diseases ([www.jrcd.eu](http://www.jrcd.eu)).

## Contact

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- **Ospedale San Raffaele** – prof. Ottavio Alfieri
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