

Development of the European Network in Orphan Cardiovascular Diseases

EU Project inauguration

Malopolska Regional Operational Programme (MROP), Priority 8. Interregional cooperation, Action 8.2.

Jakub Stępniewski, Piotr Musiałek

John Paul II Hospital, Department of Cardiac and Vascular Diseases of the Jagiellonian University, Medical College, Krakow, Poland

Both international and Polish cardiology community warmly welcomed our prior international project entitled *Establishing a European Network for Orphan Cardiovascular Diseases* (European Regional Development Fund and Małopolska Regional Operational Programme for 2007–2013). More than that, the first international project of Krakow CRCDD received wide support that enabled establishment of collaboration with our initial International Partners, and successful organization of several international symposia devoted to “no-one’s” RCD patients, including the symposium held at ESC congresses in 2012.

Therefore, efforts have been made not only to sustain this initiative but also to make it grow further.

Following our successful application, a new Project entitled *Development of the European Network in Orphan Cardiovascular Diseases* was officially launched during the quarterly CRCDD

video-consultation meeting on May 10th 2013 in the John Paul II Hospital in Krakow. The inauguration meeting was opened by the Director of the John Paul II Hospital, Dr Krzysztof Bederski (Figure 1), who expressed his appreciation for the activities of the CRCDD. He perceived the uniqueness of the Centre, which is one of the very few of this kind in Poland and also still rare in Europe. His communication was followed by Professor Piotr Podolec (Figure 1), the Head of the Centre, who acknowledged the efforts of the members of the CRCDD team put in applying for the European grant. Professor Podolec admitted that this initiative, which leading aim is to improve the quality of health care for patients affected by rare diseases of heart and vessels, could not be conducted at such a high level if not for enormous dedication of people engaged in the Project and financial support from EU. He summarized hitherto achievements of the Centre particularly appreciating the coop-



Figure 1. Dr Krzysztof Bederski (Director of the John Paul II Hospital) (right) and Professor Piotr Podolec (Head of the Centre for Rare Cardiovascular Diseases) (left) officially opening the Project and welcoming the guests



Figure 2. Mr. Wojciech Kozak, (Vice-Marshall of the Malopolska Region) discussing the role of the Project in developing the potential of Malopolska Region to improve the quality of healthcare of patients with rare diseases



Figure 3. Dr Grzegorz Kopeć (Deputy Head of the Centre for Rare Cardiovascular Diseases) discussing the aims of the Project



Figure 5. Dr Krzysztof Kłós (Director of District Hospital in Chrzanow) outlines problems that his physicians face when they manage patients with rare diseases



Figure 4. Dr Maciej Kowalczyk (Director of the University Children's Hospital of Krakow) deliberates on the need for continuity of care for patients with rare diseases



Figure 6. Regina Tokarz (Director of the Dr Tytus Chalubinski Memorial District Hospital in Zakopane) discusses the shortcomings of the national health system with regard to the care of patients with rare diseases

eration with the Project Partners, Lithuanian University of Health Sciences in Kaunas, Lithuania and the Research Institute of Cardiology, Pauls Stradins Clinical University Hospital in Riga, Latvia. Gaining the recognition at the national and international level is by far one of the most prominent successes of the Centre, mentioned Professor Podolec.

The Head of the Krakow CRCD highlighted that creating cooperation links with different European expert centres enabled selecting the most adequate management pathway for over 60 difficult rare cardiovascular patients consulted in the Centre. Recognizing the role of partnerships in the field of rare diseases, Professor Podolec welcomed 6 Partners joining the new Project. International centres establishing the formal new collaboration include *The Deutsche Herzzentrum, Berlin in Germany and San Raffaele Hospital, Milan in Italy*. New National partners are *Dr Tytus Chalubinski Memorial District Hospital in Zakopane, District Hospital in Chrzanow, Edward Szczeklik Memorial Specialized Hospital in Tarnow* and the *University Children's Hospital of Krakow*.

Before Doctor Grzegorz Kopeć, the Deputy Head of the Centre outlined the general aims of the **Development of the European Net-**

work in Orphan Cardiovascular Diseases Project, Mr Wojciech Kozak (Figure 2), the Vice-Marshal of the Malopolska Region declared his sincere appreciations for the Krakow CRCD achievements. He emphasized, that establishing the Centre was consistent with the European Union Commission Recommendations on implementation public health strategies to ensure that patients with rare diseases have access to high-quality care, including diagnostics and treatment. This improves the potential of Malopolska Region in this field at the national and international level.

Doctor Kopeć (Figure 3) stressed that fostering equal opportunities in access to up-to-date diagnostic and treatment options for patients with orphan cardiovascular diseases as the key value of the Project and the mission of the Centre.

Dr Kopec highlighted a role of education as one of primary aims for 2013–2015. He admitted that improving the quality of



Figure 7. Doktor Marcin Kuta (Director of the Edward Szczeklik Memorial Specialized Hospital in Tarnow) values the supportive role of such institutions like the Centre for Rare Cardiovascular Diseases in creating the chain of co-operation

care should be based on the improvement of knowledge and skills of the medical staff bringing aid to this unique group of patients. Therefore, sharing the expertise and know-how between Expert and non-Expert Centres remains crucial step for improving the recognition of often atypical symptoms (and, on the contrary, sometimes the symptoms commonly associated with another, more frequent disease) in the context of cardiovascular pathology, leading to shortening time to the appropriate diagnosis and management. Complexity of most RCDs and the lack of expert guidelines makes the management of these diseases exceptionally difficult. Therefore, engaging in international research cooperation and expert committees should result in formulation of diagnostic and therapeutic algorithms to support physicians in their decision making.

Doctor Kopec explained that improving the quality of care requires certain amendments in the health care system administration. For this reason, cooperation with the Polish National Health Fund, formal Partner of the Project, is directed at the elaboration of optimal rare cardiovascular diseases management models. He confirmed that formulation of internet-based, multicenter RCDs registries, recognized as a powerful apparatus in expanding knowledge on rare diseases, is in progress.

Representatives of new National Partners expressed their gratitude for becoming part of this important initiative, and presented their vision of roles in the Project.

Doctor Maciej Kowalczyk (Figure 4), Director of the *University Children's Hospital of Krakow*, referred to the durable cooperation with the John Paul II Hospital and the CRCDC in Krakow, that has lasted for many years now. He explained that many RCDs start in childhood and with the development of medical care quality these children more often reach maturity. Continuation of appropriate care in highly specialized centres is pivotal to sustain their survival.

Doctor Krzysztof Klos representing *District Hospital in Chrzanow*, Ms Regina Tokarz representing *Dr Tytus Chalubinski Memorial District Hospital in Zakopane*, and Doktor Marcin Kuta from *Edward Szczeklik Memorial Specialized Hospital in Tarnow* expressed



Figure 8. Professor Tomasz Grodzicki (Dean of Faculty of Medicine of the Jagiellonian University Medical College in Krakow) debating about the need for sharing the knowledge and experience in the field of rare diseases

their gratitude for inviting their hospitals to join the cooperation network. Doctor Klos (Figure 5) admitted that physicians in his centre more frequently face problematic cardiological cases and therefore consultation in highly specialized centres is often needed to determine optimal management. He believed that grouping the expertise in the fields of RCDs within dedicated Expert Centres is required. Ms Tokarz (Figure 6) agreed, that without reasonable changes in the national health system administration, patients with RCDs will struggle to find an appropriate medical attention. Doctor Kuta (Figure 7) was convinced that in the absence of comprehensive management strategies in majority of RCDs, distributing actual knowledge among peripheral medical institutions will support physicians in early diagnosing and proper referral of these patients.

Dean of Faculty of Medicine of the Jagiellonian University Medical College in Krakow, Professor Tomasz Grodzicki (Figure 8) focused on importance of disseminating knowledge about RCDs in promoting the future improvement of RCD patients quality of care. He expressed his determination to broaden the Medical Faculty Curriculum by topics directly referring the problem of rare diseases.

The inauguration meeting was closed by Professor Piotr Podolec, who encouraged the Partners to strengthen the cooperation networks and wished successful collaboration within the Project. All to both direct and ultimate benefit of RCD patients!

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