

World Rare Disease Day – 29th of February 2016 III Conference of Rare Cardiovascular Diseases at John Paul II Hospital in Krakow

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The third Conference of Rare Cardiovascular Diseases took place at the John Paul II Hospital in Krakow, Poland on the 29th of February 2016. The conference was organized as part of the World Rare Disease Day 2016 annually celebrated by the Centre for Rare Cardiovascular Diseases in Krakow, Poland (CRCD).

A rare disease, also referred to as an orphan disease, is any disease that affects a small percentage of the population. There is no single, widely accepted definition for rare diseases. In Europe a disease is defined as rare when it affects fewer than 1 in 2000, and in USA a disorder is defined as rare when it affects fewer than 200,000 people at any given time. 80% of rare diseases have identified genetic origins whilst others are the result of infections, allergies and environmental causes, or are degenerative and proliferative. 50% of rare diseases affect children.

The main objective of World Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

Organizing third Conference of Rare Cardiovascular Diseases the CRCD adopted the general aim of the World Rare Disease Day and invite most influential persons in the field of rare diseases in

Poland. The list of attendees included: members of the Polish Parliament, authorities of Lesser Poland Voivodeship, authorities of Marshal's Office and Krakow Municipal Council, Heads of Cardiological Departments in Malopolska, and memberships of Centre for rare Cardiovascular Disease.

The general parts of the official Programme of the conference included: (1) Educational session on rare cardiovascular diseases; (2) health care system and every-day problems of rare cardiovascular diseases patients in receiving good quality care; (3) financing the diagnosis and treatment of rare cardiovascular disease; (4) Model of Referring Patients Suffering from Rare Diseases proposed by the CRCD.

The lecture of Professor Piotr Podolec covered the issue of Rare Disease as priority in European Union. Professor Podolec reviewed the definition of rare disease and acknowledged the biggest problems faced by patients rare cardiovascular diseases patients. He also appreciated the role of European international cooperations as a framework for clinical and scientific research development leading to improvement of knowledge about rare cardiovascular diseases allowing introduction of novel diagnostic and therapeutic procedures. Professor Podolec shared with the audience the achievements of the CRCD, such as the Classification of Rare Cardiovascular Diseases, Journal of Rare Cardiovascular Diseases, Registry of Rare Cardiovascular Diseases the webpage of the CRCD (Figure 1).

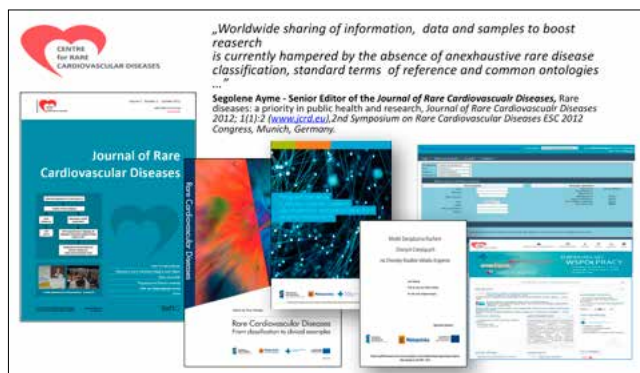


Figure 1. Main achievements of the Centre for Rare Cardiovascular Diseases in the John Paul II Hospital in Krakow, Poland: Journal of Rare Cardiovascular Diseases; Text Book of Rare Cardiovascular Diseases, Learning Programme, Web Page, Registry of Patients with Rare Cardiovascular Diseases



Figure 2. National and International Partners

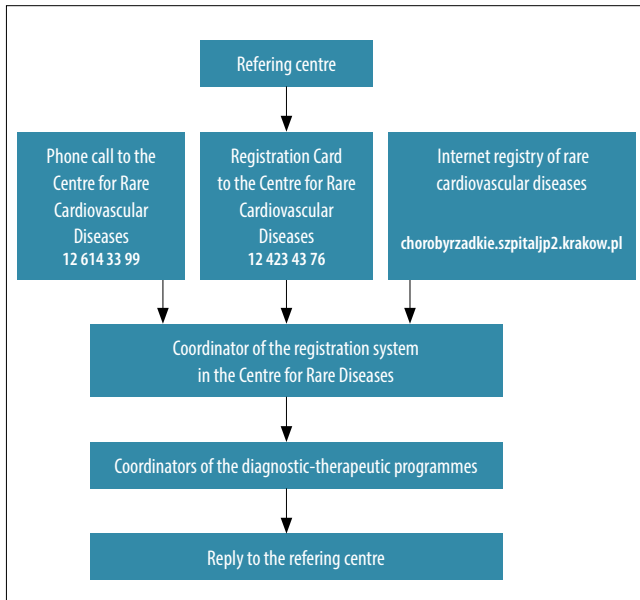


Figure 3. Model of Referring Patients suffering from Rare Disease



Figure 4. Textbook of The Curriculum in the Field of Rare Diseases for Medical Students

Professor Podolec highlighted that from 2006 to 2015, the CRCD has been instrumental in providing diagnostic path and making key decisions for 2300 patients with RCDs. Also CRCD has played an important role in the dissemination of knowledge on RCDs through symposia and conferences (ESC Congresses in Paris in 2011, in Munich in 2012, in Amsterdam in 2013, in Barcelona in 2014 and in London in 2015).

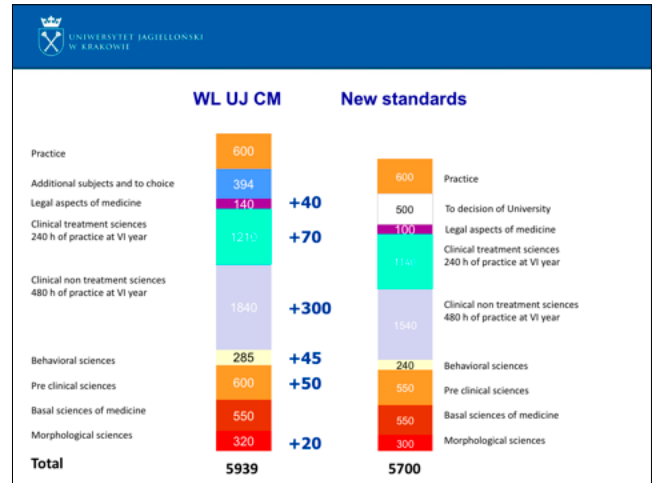


Figure 5. Teaching programme of the Faculty of Medicine of the Jagiellonian University in Krakow

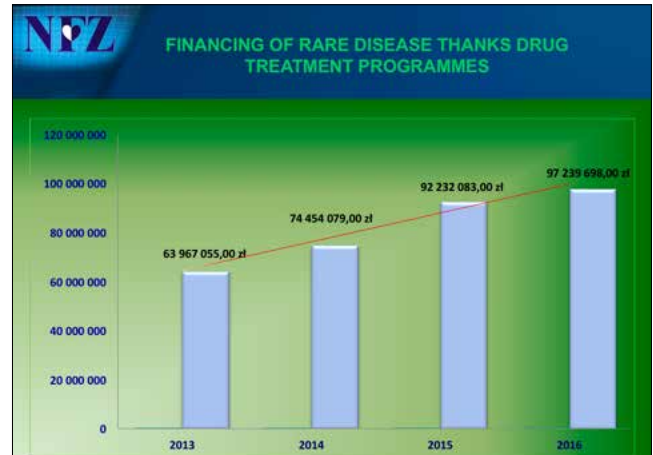


Figure 6. Financing of Rare Disease owing to drug treatment programmes

Assoc. Professor Grzegorz Kopeć talked about local cooperation of cardiology departments of Malopolska region of Poland aiming at improving care for rare cardiovascular diseases patients. Centre for Rare Cardiovascular Diseases in John Paul II hospital in Krakow is main referral centre which collaborates with provides support to all doctors of Malopolska region, who look after patients with rare cardiovascular diseases. Our partnerships are: The Edward Szczeklik Specialist Hospital in Tarnów, Municipal Hospital in Chrzanów, University Children’s Hospital in Krakow and The Tytus Chałubiński Hospital in Zakopane. Doctor Kopeć also presented Model of Referring Patients Suffering from Rare Diseases proposed by the CRCD and National Health Fund, which aims at improving the system of consultation and referral of patients with rare cardiovascular diseases to the CRCD (Figure 3).

Professor Tomasz Grodzicki, dean of Faculty of Medicine at the Jagiellonian University in Krakow, delivered a lecture on learning programme of rare diseases (Figure 4). The overall objective of the program is to raise awareness of rare diseases among medical students and doctors and increase their competence and thus improve the care of patients with rare disease. Professor Grodzicki remarked

that all students of the Faculty of Medicine in the University are taught about general problems with diagnosis and treatment of patients with rare diseases, certain diseases as examples of pathophysiology – metabolic disorders, genetic defects, etc. (Figure 5). Also students have possibility to choose supplementary course and get the knowledge of selected diseases in detail.

The last topic of the Conference was dedicated to the issue of financing of diagnosis and treatment of rare cardiovascular disease

Photo reportage – III Conference of Rare Cardiovascular Diseases at John Paul II Hospital in Krakow



Figure 7. Opening speech of the III Conference of Rare Cardiovascular Diseases at John Paul II Hospital in Krakow - Dr Anna Prokop-Staszecka MD, PhD, Director of the John Paul II Hospital in Krakow - outlined the ups and downs of the CRCD in John Paul II Hospital in Krakow throughout its 5 years of operation. She thanked to the entire CRCD team for collaboration and expressed the hope that diagnostic process and treatment of rare disease will be well funded soon



Figure 9. Assoc. Prof. Grzegorz Kopeć – focused on cooperation on rare disease with other institutions in Małopolska. He presented organizational scheme which function as part of Małopolska collaboration network and emphasised that CRCD 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 to the Center of Rare Cardiovascular Diseases

patients. The director of National Health Found in Małopolska, Ms. Elżbieta Fryzlewicz-Chrapisińska said, that funding the diagnosis and treatment of these group of patients encounter many difficulties. Mrs. Chrapisińska marked that owing to introduction of drug treatment programmes important gains continue to be made with the increase of the development of new diagnostic and therapeutic procedures (Figure 6).



Figure 8. Opening lecture: Rare Disease as priority in European Union - Prof. Piotr Podolec MD, PhD, Director of the Institute of Cardiology of the Jagiellonian University Medical College in Krakow, Poland, Head of the Department of Cardiac and Vascular Diseases and the Centre for Rare Cardiovascular Diseases at the John Paul II Hospital in Krakow – highlighted that above 2500 patients with rare cardiovascular disease have been treated in Department of Cardiac and Vascular Diseases so far. Professor Podolec thanked to Dr A. Prokop-Staszecka, and the administration team of the John Paul II Hospital in Krakow for collaboration in creation of CRCD, RCD registries, the Curriculum in the Field of Rare Diseases for Medical Students and Journal of Rare Cardiovascular Disease



Figure 10. From the left: Jakub Podolec MD, PhD, expert from CRCD; Lidia Gądek, Member of Parliament; Prof. Tomasz Grodzicki MD, PhD, Dean of Medical Faculty Jagiellonian University in Krakow and Head of the Department of the Centre for Rare at Medical University Hospital in Krakow; Dr Anna Prokop – Staszecka MD, PhD, Director of the John Paul II Hospital in Krakow, Prof. Piotr Podolec MD, PhD, Director of the Institute of Cardiology Jagiellonian University Medical College, Head of the Department of Cardiac and Vascular Diseases and the Centre for Rare Cardiovascular Diseases at the John Paul II Hospital in Krakow



Figure 11. From the left: Ewa Podłęska, Deputy Head of the Social Policy Department; Elżbieta Fryźlewicz-Chrapisińska, Director of National Health Found in Małopolska; Dariusz Madera, Director of Health and Social Policy Department



Figure 12. Mrs. Lidia Gądek MD, Member of Parliament - talked about actually status of work progress on rare diseases in Parliamentary Health Commission. Also she declared to involved CRCD in John Paul II Hospital in Krakow to the list of Ministry of Health and better financial support for rare disease in Poland



Figure 13. Mr. Dariusz Madera, Director of Health and Social Policy Department- said that establishing the Center for rare Cardiovascular Diseases at the John Paul II Hospital was prepared perfectly and thanks to Director A. Prokop-Staszecka and Professor P. Podolec could be possible to extend to a European Network for Orphan Cardiovascular Diseases

Information for authors

Aims and scope

Journal of Rare Cardiovascular Diseases (JRCD) is an international, quarterly, peer reviewed journal that keeps cardiologists up to date with rare disorders of heart and vessels. Topics covered include congenital heart defects, cardiomyopathies, rhythm abnormalities, rare forms of arterial hypertension, pulmonary hypertension, cardiac tumors and other rare diseases affecting heart and vessels such as connective tissue diseases, metabolic disorders, neuro-muscular diseases another unclassified rare diseases.

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