

# 1<sup>st</sup> International Conference on Rare Cardiovascular Diseases (Krakow, October 18–19, 2012)

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Doctors, like other academic professionals, know very well that there is no better place than a live conference to share knowledge and experience or to interact with people of similar interests.

Encouraged by the success of Rare Cardiovascular Diseases (RCD) symposia during the European Society of Cardiology (ESC) Congress in 2011 (Paris) and 2012 (Munich), the team of the Centre for Rare Cardiovascular Diseases (CRCVD) in John Paul II Hospital in Krakow organized the 1<sup>st</sup> International Conference on Rare Cardiovascular Diseases (Krakow, October 18–19, 2012). For two days, the capital of Kings of Poland became a European capital for rare cardiovascular diseases. Over 350 registered participants from the European and other countries arrived to the newly opened premises of the John Paul II Hospital Education Centre to discuss the vital aspects of care of patients with orphan cardiovascular diseases.

Raising awareness, the conference guiding phrase, expressed the fundamental goal of the meeting. The conference was designed to (1) familiarize physicians of different specialties and healthcare providers with the problems of orphan cardiovascular patients; (2) foster cooperation networks between the European Centres that already provide diagnostic and therapeutic pathways to RCD patients, (3) provide support, and include in the cooperation networks, the centers that are being established or about to be established, (4) stimulate collaborative research and knowledge dissemination; (5) broaden the perception of vulnerability of care of rare cardiovascular patients. State-of-the-art presentations by the most prominent European experts and abstracts presentations by RCD teams attracted attention and ignited the debate.

The conference was opened by the Director of Krakow CRCVD, Professor Piotr Podolec who outlined the concept and tasks of the CRCVD in Krakow and focused on the imminent and further plans of the Centre. Piotr Musiałek (Krakow, PL) gave a report on what has already been achieved, focusing on the CRCVD ESC Symposia in 2011 and 2012.

The Opening Session, chaired by Professors Tomasz Grodzicki (Krakow, PL) and Piotr Podolec (Krakow, PL) brought together most eminent cardiologists with healthcare providers from the Polish Ministry of Health and National Health Fund. Among distinguished guests and lecturers the session hosted Dr Krzysztof Chlebus from the Polish Health Ministry, Dr Krzysztof Graliński – Chairman of the National Program on Rare Diseases, Mrs. Barbara Bulanowska – President of Malopolska Division of National Health Fund, Mr. Marek Sowa – Marshal of Malopolska Region,

Dr Anna Prokop-Staszecka – Director of the John Paul II Hospital in Krakow, Professor Tomasz Pasierski – representative of the Agency for the Assessment of Medical Technologies, Professor Janina Stępińska – President of the Polish Cardiac Society, Professor Grzegorz Opolski – National Consultant in Cardiology (Poland), Professor Wojciech Nowak – Rector of Jagiellonian University Medical College, Professor Jerzy Sadowski – Director of the Jagiellonian University Institute of Cardiology. The discussion involved the scope of RCD in Poland in the context of RCD developments in Europe, and it included the burning aspects of RCD ethics, social impact and financing.

Plenary Session 2, chaired by Piotr Podolec (Krakow, PL), Adam Torbicki (Warsaw, PL) and Grzegorz Kopeć (Krakow, PL) is remembered primarily for two excellent lectures on the history and social impact of rare diseases. A European perspective was delivered by Professor John GF Cleland (Hull, UK), whereas Professor Janusz Skalski, a paediatric cardiac surgeon and medical historian (Krakow, PL), focused on the role of Polish physicians scientists in generating knowledge on orphan diseases.

The programme of the second day comprised of three scientific review sessions that were followed by oral abstracts presentations. Plenary Session 3, centered on the rare diseases associated with pulmonary hypertension, was chaired by Professors Zbigniew Gąsior (Katowice, PL), Piotr Hoffman (Warsaw, PL) and Adam Torbicki (Warsaw, PL).

Professor Nika Skoro-Sajer (Vienna, A) discussed therapeutic options for non-arterial pulmonary hypertension focusing extensively on parenteral prostacyclins. Her lecture was followed by the deliberation on the complexity of care of pregnant with pulmonary hypertension led by Professor Anna Fijałkowska (Warsaw, PL). Next, Dr Jacek Wojarski (Zabrze, PL) outlined the availability and challenges of lung transplantations for drug-resistant pulmonary hypertension patients in Poland. Finally, Dr Grzegorz Kopeć (Krakow, PL) illustrated some key RCD challenges through an example of a "rare-in-the rare" case of pulmonary veno-occlusive disease.

*Rare diseases of the heart* was the topic of the Plenary Session 4, chaired by Professors Eloisa Arbustini (Pavia, IT) and Katarzyna Mizia-Stec (Katowice, PL) and Dr Piotr Musiałek (Krakow, PL). Professor Zofia Bilińska (Warsaw, PL) focused on the role of the *family screening in inheritable cardiomyopathies* and provided evidence for the necessity of *extension of genetic testing* for Polish patients. Professor Eloisa Arbustini (Pavia, IT) presented her world-leading experience in *immunohistopathology of cardiomyopathies and its*



Announcement of the 1st International Conference on Rare Cardiovascular Diseases, 18–19 October 2012, Kraków, Poland

**clinical impact**, a lecture that will be remembered for the combined cutting-edge level of science and illustrations. Controversies in diagnosing Tako-Tsubo cardiomyopathies was the subject of Professor Egle Ereminiene (Kaunas, LT) who outlined the current diagnostic algorithm (including its shortcomings), and a **potential impact of the disease in European population**. The role of surgery in managing patients with **rare cardiac tumours** from the perspective of Deutsches Herzzentrum, headed by Professor Roland Hetzer, was presented by Professor Henryk Sieniawski (Berlin, DE). This very practical and greatly illustrated presentation **combined the experience of the leading cardiac surgery centre with the remaining unknowns**. The final presentation in the session was by Dr Pawel Rubiś (Krakow, PL) who discussed **decision-making issues associated arrhythmogenic right ventricular cardiomyopathies**; this report was supported by a down-to-the-earth description of his recent patients.

Professors Henryk Sieniawski (Berlin, DE), Jerzy Sadowski (Krakow, PL) and Jacek Musiał (Krakow, PL) chaired the Plenary Session 5 – **Rare diseases of the systemic circulation**. Current pharmacological options and surgical approach in managing some “usual” and **non-usual Marfan patients** was the matter of Professor Henryk Sieniawski (Berlin, DE) presentation. Current indications for surgery were presented and discussed, and the course of corrective surgery was beautifully illustrated. Professor Anna Kablak-Ziembicka (Krakow, PL) focused on the diagnostic and clinical impact of **rare anatomical variants of systemic arteries**, presenting an extensive set of illustrations from the imaging by her team. The need for (yet



I International Conference on Rare Cardiovascular Diseases, Krakow 2012. Prof. Janina Stępińska (President of the Polish Society of Cardiology, Warsaw) describing the role of Polish Cardiac Society in improvement of care of patients with rare cardiovascular diseases



I International Conference on Rare Cardiovascular Diseases, Krakow 2012. Dr Anna Prokop-Staszecka (Director of the John Paul II Hospital in Krakow) highlighting the role of multidisciplinary approach in care of patients with rare cardiovascular diseases. Prof. Tomasz Grodzicki (Dean of the Jagiellonian University Medical College, Kraków, Poland) and Prof. Piotr Podolec (Head of the Centre for Rare Cardiovascular Diseases at the John Paul II Hospital in Krakow) moderating the session

closer, yes!) cooperation between cardiologists and diabetologists in the context of **cardiac impact of rare forms of diabetes mellitus** was the subject of lecture by Professor Maciej Małecki (Krakow, PL). Dr Wojciech Płazak (Krakow, PL) shared his experience in managing the **circulatory system manifestations of immune-mediated syndromes** that are commonly referred to as “connective tissue” diseases. An example of **“rare-in-the rare” complex circulatory system anomalies** in a patient with congenital heart disease was discussed by Dr Lidia Tomkiewicz-Pająk (Krakow, PL).

The afternoon **Oral Abstracts Session** illustrated the current research avenues in RCD, demonstrating what has already been achieved by the enthusiasts committed to RCD patients in Europe and beyond, working on the grounds that remain largely uneasy.

From the feedback by the participants, the Conference was a success not only in terms of education, research but also broader perspectives of rare cardiovascular diseases, including their social, ethical and financial issues.

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