

# 3<sup>rd</sup> Symposium on Rare Cardiovascular Diseases – ESC Amsterdam 2013: Chairperson’s Perspective

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Continuing tradition of annual meetings, this year the Krakow Centre for Rare Cardiovascular Diseases (CRCDD) organized the 3<sup>rd</sup> Satellite Symposium during the ESC Congress in Amsterdam, the Netherlands. As in previous years, the present Symposium was an integral part of the EU Project MRPO 08.02.00-12-424/10, which is under realization by the Krakow CRCDD. The 3<sup>rd</sup> Satellite Symposium on Rare Cardiovascular Diseases was officially included in the Program of the 2013 ESC Congress and was held in the ESC Congress Venue (Rai Centre) in the Village 6, room Vienna on 2<sup>nd</sup> September 2013. For the third consecutive year the session was chaired by the world-class heart failure specialist Professor John GF Cleland from Kingston-upon-Hull, UK. The second chairmen was Doctor Paweł Rubiś from the CRCDD.

In brief, the session program followed the previously established layout of two introductory and final mini-lectures, the keynote lecture and two case-based presentations. The session was opened by the Head of the Krakow CRCDD, Professor Piotr Podolec. After a few summarizing words on the main activities of the Krakow Centre since the last meeting in Munich 2012, Professor Podolec came to the core of his lecture, which was “How to classify rare cardiovascu-

lar diseases?”. Professor Podolec briefly presented the newly developed, by the joint effort of many Experts and Partners, the Classification of Rare Cardiovascular Diseases, which was simultaneously published in the textbook of “Rare Cardiovascular Diseases: from classification to clinical examples”. Professor Podolec explained that all rare cardiovascular diseases were divided into eight classes, comprising of rare diseases of systemic and pulmonary circulation, rare diseases of the heart (cardiomyopathies), congenital cardiovascular diseases, rare arrhythmias, cardiac tumors and malignancies, rare diseases during pregnancy and last group of unclassified rare diseases. Additionally, each rare diseases is attributed with the unique code (RCD code) and widely-accepted ICD-10 code in order to ease the communication between managing physicians. It should be acknowledged that the textbook of “Rare Cardiovascular Diseases: from classification to clinical examples” was available, free of charge, for all attendees.

The Keynote Lecture, entitled “New Frontiers in cardiac surgery treatment of patients with rare cardiovascular diseases” was delivered by the Professor Ottavio Alfieri, brilliant cardiac surgeon and creator of edge-to-edge mitral valve repair (Alfieri stitch) from

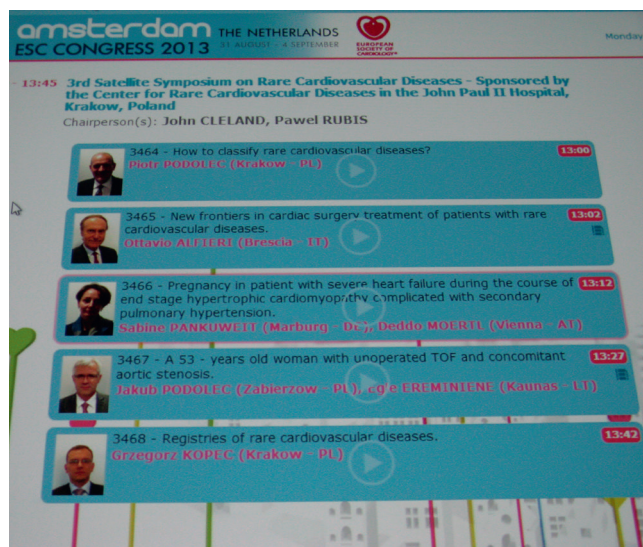


Figure 1. The graphic layout of the session



Figure 2. Professor JGF Cleland (Hull, UK) (right) and Dr P. Rubis (Krakow, PL) (left) welcome the audience and ask first presenter Professor P. Podolec (Krakow, PL) to the floor



Figure 3. Professor P. Podolec elaborates on the newly-developed Classification of Rare Cardiovascular Diseases and explains the rationale behind the classification



Figure 4. Professor O. Alfieri (Milan, IT), in the Symposium's Keynote Lecture, discusses difficulties and numerous traps when operating on patients with rare diseases

Milan, Italy. In the beginning, Professor Alfieri presented a highly complex candidate for the cardiac operation, who by the definition did not have a rare cardiovascular disease, however, due to severe course of the disease and numerous comorbidities, any decision regarding an intervention was extremely difficult and required great expertise. Therefore, Professor Alfieri stressed that not necessarily patient has to have definition-fulfilled diagnosis of rare disease to be considered truly RARE. Later, Professor Alfieri presented several excellent examples of true rare patients, mostly with complicated congenital heart diseases, who were expertly managed in his Centre.

There were two case-based presentations on rare diseases and on the optimal management strategy in the middle of the session. Each presentation was delivered by the managing physician from the Krakow Centre and commented by two national and international Experts.

The first case on the inherent difficulties and uncertainties on the management of pregnant patient with heart failure on the basis of end stage hypertrophic cardiomyopathy, which was additionally complicated with secondary pulmonary hypertension, was presented by Doctor Lidia Tomkiewicz-Pajak. The case was discussed by Professor Sabine Pankuweit from Marburg, Germany and Professor Deddo Moertl from St. Poelten, Austria. Professor Pankuweit, who is an expert in cardiovascular genetics, commented on the molecular mechanisms that may have caused the transition from the compensated hypertrophic cardiomyopathy to its

burned-out phase. Professor Pankuweit stressed the potential role of molecular studies in the future, however, at the same time underlined that at present we are not ready yet... Professor Moertl, who is an expert in the management of pulmonary hypertension, stressed the importance of highly accurate hemodynamic measurements, that may have a decisive role in the prescription of adequate pharmacotherapy.

The second case on the management of middle-age woman with unoperated tetralogy of Fallot (ToF) and concomitant aortic stenosis was delivered by Associate Professor Andrzej Gackowski, and discussed by Professor Egle Erminiene from Kaunas, Lithuania and Doctor Jakub Podolec from Krakow Centre. Professor Erminiene, being a specialist in cardiac imaging, commented on the difficulties and also on the tips and tricks related to the establishment of the proper diagnosis in a patient with an uncorrected ToF, complicated with some other cardiac abnormalities. Doctor Jakub Podolec, an invasive cardiologist, discussed the best possible management strategy, including pros and cons of surgical intervention as well as potential percutaneous correction of aortic stenosis.

The final presentation of the symposium was given by Doctor Grzegorz Kopeć from the CRCDC. Doctor Kopeć focused on the important topic of registries of cardiovascular diseases. There is no doubt that registries, especially in the field of rare diseases, are invaluable source of epidemiology data and should be a cornerstone of any balanced financial decision. Moreover, Doctor Kopeć pre-





Figure 5. Right after the session. Ad hoc discussions between (from the right) Professors Garry Webb (Cleveland, US), Prof P. Podolec, Prof O. Alfieri and Doctors J. Podolec, A. Gackowski and L. Tomkiewicz-Pająk (Krakow, PL)



Figure 6. Right after the session (from the left) Professor D. Moertl (St. Poelten, AT), specialist in pulmonary hypertension, Professor Sabine Steiner (Vienna, AT), specialist in angiology and Dr G. Kopec (Krakow, PL), specialist in pulmonary hypertension

sented a couple of examples of registries that incorporate the structure of newly-developed Classification of Rare Cardiovascular Diseases. Finally, Doctor Kopec encouraged the audience to visit a designated web-page for rare cardiovascular diseases ([www.crcd.eu](http://www.crcd.eu)) as well as to submit a paper to the Journal of Rare Cardiovascular Diseases.

As in previous years, the lecture hall was nearly too small to accommodate the high turn-up of participants. Among many distinguished guests, we hosted Professor Garry Webb from the Cleveland Clinic, USA, Professor Piotr Hoffman from National Heart Institute, Warsaw, Poland, and many others. Unfortunately, due to time restrictions (scheduled time of 45 minutes), not everyone could actively participate in the vivid debate during the session. However, many participants stayed long outside the room to carry on with the ad hoc debate and discussions.

In summary, the highly interesting content of the session and case-based format of the lecture, has been once again a magnet for a high turn-up of participants from all over the world, many of whom took part in this meeting for a third time. This year, the great debate concentrated on the newly-proposed Classification of Rare Cardiovascular Diseases. As every voice count, right after the session the decision has been made to contact all session participants to ask them formally to share their view on the classification. At the moment, we are impatiently awaiting responses that have already started coming ...

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