

Highlights from the Polish Pulmonary Hypertension Patients and their Friends Meeting in Krakow

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Annual Meeting of the Pulmonary Hypertension Patients and their Friends organized by Pulmonary Hypertension Association (PHA) of Poland was held on June 11, 2016 at the Department of Cardiac and Vascular Diseases of the John Paul II Hospital in Krakow, a referral pulmonary hypertension (PH) Centre. The Meeting attracted a great number of PH patients with their families and caregivers. More than 130 participants were hosted by the Director of the John Paul II Hospital – dr Anna Prokop-Staszecka, the Head of the Department of Cardiac and Vascular Diseases – prof. Piotr Podolec, the Coordinator of the PH Programme – assoc. prof. Grzegorz Kopeć, and the President of PHA Poland – Mrs Alicja Morze, to spend a pleasant afternoon together and talk about lights and shadows of being a PH patient or a relative or a caregiver of such.

Welcome lecture was given by Prof. Piotr Podolec, who reviewed different types of PH and discussed current and emerging therapeutic possibilities. He stressed upon diversity of PH and specificity of available PH medications.

‘Questions and answers’ format was adopted for the next session. Prof. Grzegorz Kopeć with his colleagues, who everyday care for patients with PH, discussed some of the most common concerns and uncertainties expressed by patients and their relatives.

Dr Wojciech Magoń was asked, whether travelling by plane is safe for patients with PH? He stated, that despite the lack of scientific proofs on whether it is or it is not safe, a great number of PH patients do travel by plane worldwide without known complications. He advised however, that some important preparations should be done before the flight. The patient should have a visible, written information on her/his disease. She/He should inform flight provider about her/his condition and make sure that, whenever needed, an in-flight O₂ supplementation must be available for her/him. She/He should additionally know how to contact local PH clinic at their destination, in case anything happens.

Dr Anna Tyrka addressed to an issue of vaccinations in PH patients. She confirmed that patients with PH are susceptible to development of potentially life-threatening pneumonia. For this reason – She stressed – all patients with PH should vaccinate against influenza virus and pneumococcal pneumonia once a year.

Dr Marcin Waligóra faced a question, whether catheter for epoprostenol infusion hurts? He began his comment with a clear assur-

ance that prostacyclin analogue, epoprostenol, is one of the most, if not the most, efficient medication for pulmonary arterial hypertension today. He stated however, that due to a short half-life time (3–5 minutes) it requires delivery by an infusion pump via permanent tunneled catheter called Hickmann catheter. He then elegantly described the whole implantation procedure asserting it is pain-free by the use of local anesthesia and discussed potential short and long-term complications. He confirmed, that having a Hickmann catheter doesn't hurt and the risk of infections or other complications is minimized with an appropriate training and cooperation.

“Will my children have PH?” was the question answered by Dr Kamil Jonas. He acknowledged, that idiopathic arterial pulmonary hypertension may be caused by a genetic mutation. Heritable pulmonary arterial hypertension, however, represent less than 4% of all pulmonary arterial hypertension cases. He explained, that the risk of developing PH in offspring of an affected patient is rather low, estimated for 2–10% depending on the family history. In some patients with specific types of PH, like pulmonary veno-occlusive disease or pulmonary capillary haemangiomatosis, genetic counseling may be indicated.



Figure 1. P First participants arrive to the Congress Centre of the John Paul II Hospital in Krakow



Figure 2. Pulmonary Hypertension Patients and their Friends, together

The next session was dedicated to the Association of Pulmonary Hypertension Patients and their Friends. Mrs. Alicja Morze introduced the board of the Association and people related to the Association. She described scope and aims. She overviewed past achievements and future goals. She underlined that the Association is composed of PH patients for PH patients.

Formal part was concluded by a lecture entitled 'When you are sick for ever – psychological consequences of chronic illnesses' delivered by clinical psychologist, Anna Kędzierska. The lecture, concerning various aspects of coping with difficult moments during any chronic disease, eventually put all in optimistic and hopeful spirit.

Long after the lectures had the talks and discussions continued. All participants agreed that such meetings are important and should be repeated even more often.

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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