

# 1st Conference for Adults with Congenital Heart Diseases. “Care for congenital heart disease patients in Poland”

**Lidia Tomkiewicz-Pajak**

Department of Cardiac and Vascular Diseases, Institute of Cardiology, Jagiellonian University Medical College, Centre for Rare Cardiovascular Diseases, John Paul II Hospital, Krakow, Poland

The population of adults with congenital heart disease (ACHD) is heterogeneous with respect to the type and complexity of the defect as well as its clinical manifestations. In many patients congenital heart disease (CHD), after corrective surgery in the childhood, does not affect significantly their adult life. However, some of them require multispecialist care. These adult patients with moderate and extremely complex CHD, despite reaching their adulthood are unable to function independently in the society.

CHD affects everyday life in many different ways. Some patients are inclined to believe that they are “different” from the rest. They are raised very frequently by overprotective parents. Such symptoms as cyanosis, changes in their fingernails or scars make them perceive their own body as being far from normal and physically less attractive. Their relationships with friends are frequently dysfunctional, they frequently miss lessons, sometimes pursue individual educational plans, do not participate in elective courses, experience reduced exercise tolerance. The feeling of being different usually is stronger during puberty. This may lead to developmental, emotional and social problems in some adolescents and adults with congenital heart disease. They are most frequently memory disorders, attention problems, difficulty in planning, impaired intellectual and educational development. These problems are partially related to the impact of the society thus enhancing psychological

difficulties and decreasing self-confidence. They also have a problem with planning a family and pregnancy.

There is a „new” group of patients all over the world who require a different management strategy. Apart from medical care provided in specialized centers, it is indispensable to establish a model of professional mobilization for these young people. It is pivotal to identify individual needs, provide motivation and psychological support for these returning to work. Patients associations play a very important role, their mission is to improve and extend the lives of all born with heart defect through education, advocacy and promotion of research.

1st Conference for Adults with Congenital Heart Diseases took place on 30th of May 2014 in Krakow, Poland. It was organized by Working Group in Congenital Heart Diseases of Polish Society of Cardiology and Centre in Rare Cardiovascular Diseases in John Paul Hospital, Krakow. Its objective was to present the most common problems and late complications in adults with congenital heart diseases. There was also time for meeting and making friendships. The event was composed of 4 sessions. The lectures were held by the most outstanding specialists in congenital heart diseases.

The keynote lecture was given by a professional cyclist Rafał Siwiec who has paresis of lower limbs after a bike accident. He beauti-



**Figure 1.** The conference was attended by 200 participants



**Figure 2.** Experts discussion before conference: (from the right) Professor Piotr Podolec (Krakow), Professor Mirosław Kowalski (Warszawa), doctor Lidia Tomkiewicz-Pajak (Krakow)



**Figure 3.** Professor Piotr Hoffman (Warszawa) and doctor Lidia Tomkiewicz-Pajak (Krakow) with a Guide for Adults with Congenital Heart Diseases



**Figure 4.** Registration for conference – Katarzyna Parafianowicz – The Head of Board of Trustees Foundation Serce Dziecka im. Diny Radziwiłłowej

fully described how people can overcome illnesses. The next lecture entitled “Care of patients with congenital heart diseases in Poland” was given by Professor Piotr Hoffman, who explained why managing adults patients with congenital heart diseases has become a burning medical and public health problem all over the world. He also presented the main Polish centers for adults with congenital heart diseases. Professor Anna Klisiewicz (Warszawa) presented pathomechanisms of most common late complications. Doctor Krystyna Komnata (Krakow) very clearly analyzed the lung disorders in patients with congenital heart diseases. Professor Jacek Lelakowski (Krakow) discussed the problem of arrhythmia and indications for pacemaker implantation and answered the question how a patient with pacemaker can live. During the next session a very important and relevant subject- pulmonary hypertension in patients with congenital diseases – was discussed. Professor Piotr Podolec (Krakow) presented the frequency of occurrence and diagnostic methods and new possibilities of treatment. Endocarditis is one of the most common and potentially life-threatening late complication in population with congenital heart disease. For this reason Professor Maria Olszowska (Krakow) presented indications and recommendations regarding prophylaxis. Although the prevalence, risk factors, and management of thromboembolic complications in some congenital heart diseases have been well described, for the management of



**Figure 5.** Rafał Siwiec during a lecture

others there is a paucity of data, and controversy exists even among experts. Professor Anetta Undas (Krakow) discussed the problem of antithrombotic treatment in this group of patients.

The third session, was dedicated to the problems connected with pregnancy and physical activity. An important caveat with ACHD is that most women with a congenital heart disease, if offered proper care, can have a successful pregnancy. Doctor Lidia Tomkiewicz-Pajak (Krakow) presented risk factors to the mother and to the fetus during pregnancy. She also pointed to the need for consultation from an Adult Congenital Heart Center prior to becoming pregnant in order to review their individual risks. Professor Krzysztof Rytlewski (Krakow) presented the problem of using contraceptives by women with CHD. Anyone with congenital heart disease, repaired or non-repaired, should consult with their cardiologist about physical activity to eliminate the risks of undertaking it. Doctor Monika Komar (Krakow) presented advice to patients with CHD if they want to practice sport safely.

During the last session Professor Bohdan Maruszewski (Warszawa) and Professor Grazyna Brzezinska-Rajszyz as well as all the other speakers and experts answered the patients' questions. It was a very interesting part of the conference. Clinical psychologist Karolina Barczyk (Krakow) presented main psychological and emotional problems in ACHD and advised how to deal with them.

The conference was attended by 200 participants. All the lectures were very stimulating and inspired interesting discussions between the experts and the participants. In conclusion, it was an important congress, which proved a need to organize conferences dedicated to patients and cooperation between Adult Congenital Heart Centers and patients' association in education, advocacy and promotion of research on ACHD. We are going to organize the next conference in November 2015. All the details will be available at [www.guchptkardio.pl](http://www.guchptkardio.pl).

# Information for authors

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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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